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Advancing Measurement of Patient-Centered Communication in Cancer Care

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Advancing Measurement of Patient-Centered Communication in Cancer Care

Structured Abstract

Background. This is a second-phase project sponsored by AHRQ and the National Cancer Institute through the DEcIDE program. Phase 1 developed a framework for measuring patient-centered communication (PCC) in cancer care, including identifying measurement domains and subdomains for the following six functions (Epstein & Street, 2007): exchanging information, fostering healing relationships, recognizing and responding to emotions, managing uncertainty, making decisions, and enabling patient self-management.

Objectives. The goal of Phase 2 was to refine the Phase 1 framework; identify, develop, and test PCC measures; and create surveys for patients and health care professionals. These surveys were intended to assess PCC in cancer care at the organizational and population levels.

Approach and methods.

Refine Measurement Model/Scientific Evaluation Group (SEG): Refined the PCC framework and mapped the existing domains/subdomains to the refined model. This process was guided by an independent SEG, and members had expertise in clinical cancer communication, survey design, cognitive testing, and health care delivery and quality of care.

Develop and Test Measures: We developed an inventory of PCC survey items by examining published literature and soliciting expert and public input. We then cataloged the existing items, identified gaps, and developed new items as appropriate. Finally, we pre-tested the survey items with cancer patients (n=46) in various settings who have diverse cancer types and are in various stages of care.

Create Surveys: We developed self-administered surveys for both patients and health care providers. The two patient surveys (a) monitored quality of care in health care organizations and (b) captured population-level surveillance. The provider survey assessed clinicians' PCC activities.

Results. We retained the existing PCC framework as the foundation for developing the survey items. We identified relevant survey items from a total of 83 existing instruments and mapped them to the PCC domains. The process resulted in the creation of a pool of 1,316 survey items. However, 75 percent of these items did not meet our criteria for inclusion and were not retained. The number of items retained varied widely by domain area, requiring new items to be developed. During pre-testing, the items functioned well overall. The cancer patients who participated in the testing were generally able to understand the questions, apply them to their own experiences, and use the response scales to choose an appropriate answer. Many participants reflected that the items measured important aspects of their interactions with clinicians. We made numerous recommendations about how to revise and word the items.

Conclusions. This project lays the groundwork for the assessment of PCC in cancer care. We used a systematic approach to develop PCC items for a patient survey, beginning by inventorying existing survey and other measurement instruments and items. Subsequently, we developed and tested a total of 220 items, and ultimately finalized a set of 147 candidate PCC items. Additional steps are needed to finalize the items including additional cognitive testing, conducting a large-scale field test of the items followed by psychometric analysis, and finalizing the items and developing short and long-term versions of measures.

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Introduction

In 2007, RTI International began work on “Advancing Measurement of Patient-Centered Communication in Cancer Care,” a project sponsored by the National Cancer Institute (NCI) and the Agency for Healthcare Research and Quality (AHRQ) and funded through AHRQ’s Developing Evidence to Inform Decisions about Effectiveness (DEcIDE) program. The overarching goal of this project was to lay the groundwork for monitoring and assessing patient-centered communication (PCC) in the context of cancer care.

Phase 1 of the project aimed to operationalize PCC for the purpose of measurement using the NCI conceptual model of PCC as a framework.^a To achieve this, we identified measurement domains and subdomains for each of the six functions of PCC as defined in the model:

(1) fostering healing relationships, (2) exchanging information, (3) making decisions, (4) enabling patient self-management, (5) managing uncertainty, and (6) responding to emotions.

The goals of Phase 2 of the project were to (1) refine and finalize the conceptual model of PCC; (2) develop measures for the key PCC constructs in the context of the PCC framework, including creating an inventory of existing measures and new candidate items for a patient survey; (3) conduct cognitive testing of candidate survey items; and (4) create survey items for patients and provide guidance for a parallel survey for health care professionals.

This Phase 2 final project report comprises sections related to the following objectives:

- **Objective 1: Refine Measurement Model**—This section presents the process used to review and finalize the PCC conceptual model and measurement domains and subdomains based on consideration of relevant theories. To that end, we conducted a meeting with the Scientific Evaluation Group (SEG) and other experts in the field to obtain input on the measurement model.
- **Objective 2: Develop PCC Measures**—This section describes the development of a PCC item bank, beginning with developing an inventory of relevant surveys and other instruments and existing items, identifying the items most relevant to the PCC functions, and revising existing items and developing new items to fill gaps in the inventory.
- **Objective 3: Cognitive Testing of PCC Items**—This section presents the methods and findings from the cognitive testing of candidate PCC items with cancer patients, and includes recommendations for next steps, such as the need for further formative research in some areas, additional cognitive testing, and field testing of PCC items.
- **Objective 4: Considerations for Developing a Physician Survey To Assess PCC**—This section provides guidance for the future development of survey questions for physicians. It includes a discussion about the goals and framework for a physician survey, important considerations for measurement development, and the roadmap for instrument development.

A final section presents considerations for next steps in PCC measurement development.

^aEpstein RM, Street RL Jr. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007.

Objective 1: Refine Measurement Model^b

Advancing Measurement of Patient-Centered Communication in Cancer Care Expert Advisor Meeting

Patient-centered communication (PCC) is of particular importance in the context of care for cancer and chronic health conditions where interactions between patients and providers occur over extended periods of time and frequently involve multiple clinicians. The National Cancer Institute's (NCI's) PCC conceptual model defines six functions of communication: (1) fostering healing relationships, (2) exchanging information, (3) making decisions, (4) enabling patient self-management, (5) managing uncertainty, and (6) responding to emotions.¹

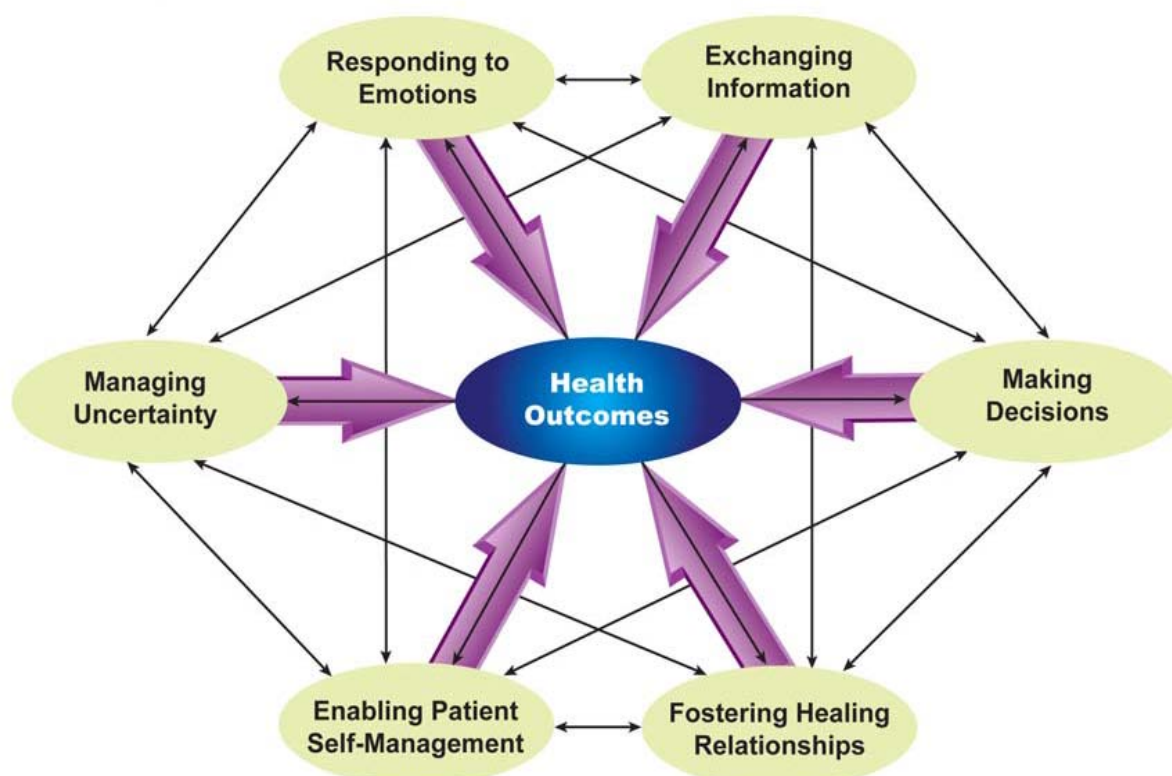
RTI International was funded initially in 2007 to advance the measurement and monitoring of PCC. To this end, in the first phase of the project, we (1) updated the literature review in the NCI monograph to include current literature; (2) conducted limited primary data collection involving observations of medical encounters and in-depth interviews with cancer patients and family members to provide further insight into PCC measurement domains and subdomains; (3) established and collaborated with expert teams focusing on each PCC function to identify measurable domains and subdomains; (4) developed an inventory of PCC measurement domains and subdomains; and (5) conducted meetings with NCI and Agency for Healthcare Research and Quality (AHRQ) scientific staff, expert advisers, and Scientific Evaluation Group (SEG) members.

The second phase of the project aims to (1) refine and finalize the conceptual model of PCC and identify measurable domains and subdomains associated with each major construct in the model (see Figure 1), (2) develop measures for the key PCC constructs as identified in the model, (3) test measures using a cognitive interviewing and cognitive appraisal approach, and (4) develop final patient surveys and a brief health care professional survey. As a first step, AHRQ, NCI, and RTI convened a 1-day expert meeting on December 17, 2009, to review and finalize the PCC conceptual model and measurement domains/subdomains based on consideration of relevant theories and input from the SEG and other experts. The first objective of the meeting was to determine whether there was a need to refine the existing conceptual model because of possible limitations, including the following:

- The functions are complex, involve multiple components, and overlap with one another.
- A hierarchy of functions may provide clarity or guidance in the measurement process.
- All theoretical and clinical issues may not be explicitly addressed.

^bPrepared by: Lauren McCormack, Ph.D.; M.S.P.H., Katherine Treiman, Ph.D., M.P.H.; Pam Williams Piehota, Ph.D.; Douglas Report, M.P.H.; Murrey Olmsted, Ph.D.; Rebecca Moultrie, RTI International, Research Triangle Park, NC.

Figure 1. Six domains of communication and health outcomes



Source: Epstein, R. M., & Street, R. L., Jr. Patient-centered communication in cancer care: Promoting healing and reducing suffering. NIH Publication No. 07-6225. Bethesda, MD: National Cancer Institute; 2007.
www.outcomes.cancer.gov/areas/pcc/communication.

Ultimately, the team determined not to make any revisions to the PCC conceptual model at this time and will continue to use it as a blueprint for moving forward with the measurement development process. Instead, the focus should be on ensuring that the PCC model is comprehensive and developing solid measures for each function. Once the measures are finalized, empirical testing can be conducted to determine whether the model needs to be refined, for example, to determine if the functions make sense as distinct constructs and delineate the pathways among functions.

This report contains a high-level summary of the meeting, as well as more detailed notes and meetings materials.

Objective 2: Develop PCC Measures^c

Introduction

Patient-centered communication (PCC) is of critical importance in the context of care for cancer and chronic health conditions where interactions between patients and providers occur over extended periods of time and frequently involve multiple clinicians. As part of an initiative on PCC, the National Cancer Institute (NCI) developed a conceptual model that defines six functions of PCC: (1) fostering healing relationships, (2) exchanging information, (3) making decisions, (4) enabling patient self-management, (5) managing uncertainty, and (6) responding to emotions¹ (see Figure 1).

RTI International was funded initially in 2007 to advance the measurement and monitoring of PCC. To this end, in the first phase of the project, we (1) updated the literature review in the NCI monograph to include current literature; (2) conducted limited primary data collection involving observations of medical encounters and in-depth interviews with cancer patients and family members to provide further insight into PCC measurement domains and subdomains; (3) established and collaborated with expert advisors, including researchers and clinicians, focusing on each PCC function to identify measurable domains and subdomains; (4) developed an inventory of PCC measurement domains and subdomains; and (5) conducted meetings with NCI and the Agency for Healthcare Research and Quality (AHRQ) scientific staff and expert advisors for the project (see Appendix E).

The second phase of the project has four objectives: (1) refine and finalize the conceptual model of PCC; (2) develop measures for the key PCC constructs as identified in the model, including creating an inventory of existing measures and creating new candidate items; (3) conduct cognitive testing of candidate measures; and (4) develop a final patient survey and summarize lessons learned from the patient survey and implications for future development of a provider survey.

This report presents work conducted under Objective 2: Develop PCC Measures. We describe the development of a PCC item bank beginning with inventorying relevant instruments and existing items; the culling process to identify the items most relevant to the PCC functions; and revision of existing items and development of new items to fill gaps in the inventory.

Development of PCC Item Inventory

The goal of this phase of Objective 2 was to develop a comprehensive inventory of candidate measures of PCC. We accomplished this objective in a two-step process. First, we developed an inventory of key survey instruments, question banks, and other instruments that could potentially be used to assess PCC in cancer care. Second, we identified specific items from these instruments and mapped them to the PCC functions and measurement domains. A brief description of these processes and their outcomes is provided below.

Instrument Inventory

The project team identified relevant survey instruments, question banks, and other instruments in several ways:

^cPrepared by: Murrey Olmsted, Ph.D.; Samruddhi Thaker, Ph.D.; Rebecca Moultrie; Katherine Treiman, Ph.D., M.P.H.; Lauren McCormack, Ph.D., M.S.P.H.; RTI International, Research Triangle Park, NC.

- Reviewed the NCI monograph “Patient-Centered Communication in Cancer Care.”¹ The monograph identifies a number of PCC measurement tools for patient self-report and other data collection modalities.
- Consulted with the project’s expert advisors, all of whom are active researchers in the field and have up-to-date knowledge about PCC-related research activities.
- Reviewed peer-reviewed and grey literature relevant to PCC.

In addition, we issued a request for input in the Federal Register (Vol. 75, No. 42, March 4, 2010) to invite organizations and individuals who have developed surveys or survey items relevant to PCC to submit them for possible inclusion in the inventory. We prepared a joint announcement with the team conducting research for the cancer Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey requesting input for both projects. No input was received in response to this announcement.

For the initial inventory, we included instruments that contained items or scales relevant to one or more of the PCC functions and domains (see initial function and domain lists in Appendix F). We sought instruments that were available for review or for which detailed descriptions were available. At this stage, we also included some instruments that were referenced in journal articles or other sources, but about which we had only limited information. We flagged these for review, and depending on feedback from the project team, we sought to locate the original questions referenced.

We did not review provider measures initially but flagged them for later review by NCI, AHRQ, and the expert advisers; we reviewed those items deemed relevant and adapted them to address patient measures of PCC.

We identified a total of 174 eligible surveys and questionnaires for inclusion in the instrument inventory. For each instrument, we documented the instrument name, citation, authors, whether it was referenced in the PCC monograph, whether the instrument is proprietary, and whether it is publicly available or otherwise accessible. To narrow down the list of instruments to those with greatest relevance, we prioritized those that met any of the following criteria:

- Closely aligned with the PCC functions and domains
- Referenced in the NCI monograph
- Designed for patient self-report (vs. observational coding or other data collection methods)
- Identified as a key instrument by members of the project team

We identified a total of 83 instruments and/or surveys as high priority using these criteria. Appendix G provides the list of all 174 instruments and indicates these 83 priority instruments.

Item Inventory

The next step involved identifying the relevant items in the 83 prioritized instruments and mapping them to the PCC functions and domains. We identified a total of 1,316 items and organized them in an inventory spreadsheet that provides the following information for each item: the source, item wording, response options, administration format (e.g., paper-pencil self-report, telephone, interview administered, observation/coding system), population of focus (e.g., patients, physicians, other health care professionals), year published, reference, and any notes (see Appendix H).

To test the process of mapping items to the PCC functions and domains, we conducted an exercise in which project team members from RTI, NCI, and AHRQ and the expert advisors independently categorized items from a sample instrument (the Communication Assessment Tool developed by Makoul et al., 2007²). The team discussed the results of the exercise and established consistent rules for categorizing the items by function. The team determined that agreement at the function level was a priority for categorization and agreement at the domain level was secondary. In addition, the team agreed that if items appeared to fit well in more than one function they would be categorized as follows:

- Items appearing to fit into the fostering healing relationships function and another function were categorized as being part of the other function.
- Items appearing to fit into the enabling self-management and making decisions functions were categorized as being part of the making decisions function.

Two senior RTI researchers independently categorized a total of 1,316 items. The coders were consistent in identifying the PCC function and domain in 1,237 of the 1,316 items (94%). The researchers reviewed the items for which there were discrepancies and resolved the coding by consensus. Figure 2 provides an overview of the inventory process and results.

Figure 2. Process and results of the PCC inventory

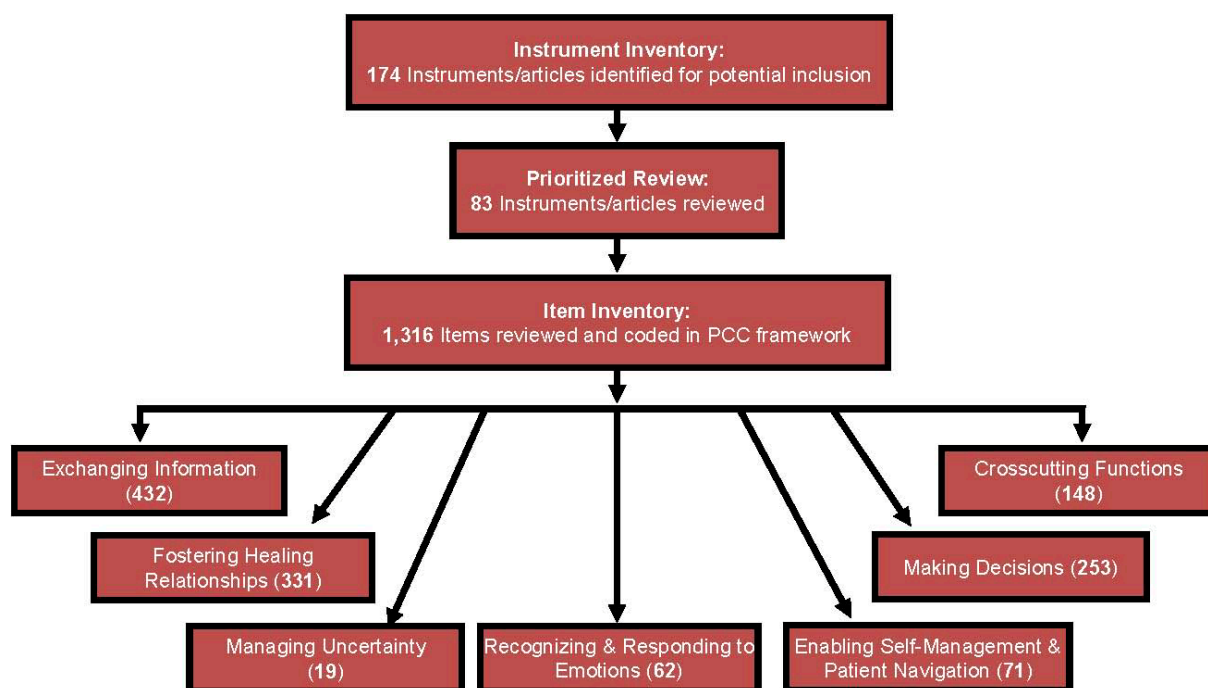


Table 1 presents a breakdown of the numbers of items identified by each function and domain. We identified the largest number of items for the exchanging information (432 items) and fostering healing relationships (331 items) functions. In contrast, few items were identified for the managing uncertainty (19 items) and recognizing and responding to emotions (62 items) functions. Within each function, there were differences in the numbers of items relevant to the domains. For example, in exchanging information, we identified only 30 items related to providing information resources compared to 233 items related to sharing information.

Table 1. PCC item inventory counts by function and domain

Exchanging Information (432 items)
<ul style="list-style-type: none"> • Exploring knowledge, beliefs, and information needs and preferences (67 items) • Sharing information (233 items) • Providing informational resources and helping patients/family members evaluate and utilize resources (30 items) • Facilitating assimilation, understanding, and recall of information (102 items)
Fostering Healing Relationships (331 items)
<ul style="list-style-type: none"> • Discussion about roles and responsibilities (25 items) • Honesty, openness, disclosure (47 items) • Trust in clinician's technical competence, skills, and knowledge (64 items) • Expression of caring and commitment (106 items) • Building rapport, connection and respect (89 items)
Managing Uncertainty (19 items)
<ul style="list-style-type: none"> • Constructing and defining uncertainty (2 items) • Assessing and understanding uncertainty (cognitive) (2 items) • Using emotion-focused management strategies (affective) (12 items) • Using problem-focused management strategies (behavioral) (3 items)
Recognizing and Responding to Emotions (62 items)
<ul style="list-style-type: none"> • Expression of emotions (23 items) • Exploring and identifying emotions (8 items) • Assessing depression, anxiety, or psychological distress (4 items) • Acknowledgement and validation emotions (9 items) • Expression of empathy, sympathy, and reassurance (12 items) • Providing tangible help in dealing with emotions (6 items)
Enabling Self-Management and Patient navigation (71 Items)
<ul style="list-style-type: none"> • Learning and assessing (8 items) • Sharing and advising (23 items) • Prioritizing and planning (4 items) • Preparing, implementing, and assisting (9 items) • Arranging and following-up (12 items) • Patient navigation (6 items)
Making Decisions (253 items)
<ul style="list-style-type: none"> • Communication about decisional needs, decision support, and decision process (77 items) • Preparation for the decision and deliberation (120 items) • Making and implementing a decision and action plan (31 items) • Assessing decision quality and reflecting on choice (25 items)
Cross Cutting (148 items)
<ul style="list-style-type: none"> • Time for communication (32 items) • Setting for communication (14 items) • Communication about team roles and coordination (11 items) • Basic interpersonal communication skills (91 items)

PCC Item Bank Culling Process

The PCC item inventory process generated a large number of items that could potentially be used to assess PCC in cancer care. However, many items were redundant, did not fit the PCC framework well, or were poor quality compared with other items. We undertook a process to identify items that should be retained or excluded as the project moves forward.

To facilitate this process, the project team developed criteria for item review. Two RTI senior researchers reviewed all items in the bank and coded each item into one of three categories: 0 = exclude; 1 = retain for use, will require extensive revisions; and 2 = retain for use, will require minimal revisions. We documented initial recommendations for retaining and excluding items in separate spreadsheets and archived them for future reference. Next, we

reviewed all items and conducted adjudication for items where there was a lack of agreement. The RTI team discussed these items to arrive at a consensus opinion, which was then documented in a final master spreadsheet.

Overall, this process resulted in the recommendation to exclude 75% (983) of the items in the item inventory (coded as “0”). We based the recommendation to drop these items on the following considerations (examples provided for each):

- Item does not align well with the PCC functions and specific domains and subdomains (e.g., “It is often best if a patient does not have the full explanation for a medical procedure.”).
- Item is vague or unclear (e.g., “Physicians and patients were confident they were on the same wavelength.”).
- Item is designed for an observational study only and cannot be easily assessed through patient self-report (e.g., “Physician makes reference to patient’s emotional state.”). Note that some observational measures were retained because they are adaptable for patient self-report.
- Item is focused on customer service, self-efficacy, patient preference, etc., which is unrelated to PCC (e.g., “Patient satisfaction with the way their needs were addressed.”).
- Item is redundant and lower quality than other available item(s) measuring the same concept (e.g., wording not as clear).
- Item is too specific to a phase or type of cancer treatment (e.g., “In transitioning to palliative care, the physician checks that the patient has understood the conversation.”).

We retained items scored as either a 1 or 2 for review during the next step of the item development process. Items with a score of 1 represented items deemed to include some key idea or kernel of information important to the PCC framework’s functions and/or domains; however, these items also showed problems in wording or conceptual clarity requiring extensive revision before use as measures of PCC. For each item retained with a score of “1,” we included a brief explanation to document the kernel or idea deemed important from the item to measure PCC. Items deemed to be of higher quality were given a score of “2,” indicating that they be retained and need minimal revision before use as measures of PCC. The most common reason for dropping items was because they were repetitive and lower quality than other comparable items assessing the same construct. A breakdown of the results of the culling process is shown in Table 2.

Table 2. Results of item culling process by function

Function	Total Items Prior to Culling	Exclude	Retain, Requires Extensive Revisions	Retain, Requires Minimal Revisions
		Coded 0	Coded 1	Coded 2
Exchanging information	432	358	69	5
Fostering healing relationships	331	258	66	7
Managing uncertainty	19	6	11	2
Recognizing and responding to emotions	62	27	35	0
Enabling self-management and patient navigation	71	38	32	1
Making decisions	253	189	60	4
Cross-cutting functions	148	107	41	0
Totals	1,316	983	314	19

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Table 3 presents the findings from the culling process for each function and domain. For each function, the total numbers of items coded as 0, 1, and 2 are listed to the right of each function. In reviewing the breakdown of recommendations for retaining items at the domain level, it is evident that the number of items retained by domain varied widely.

Table 3. Results of the culling process by function and domain

	Exclude	Retain, Requires Extensive Revisions	Retain, Requires Minimal Revisions
Function/Domain	Coded 0	Coded 1	Coded 2
Exchanging Information	358	69	5
Exploring knowledge, beliefs, and information needs and preferences	49	17	1
Sharing information	206	26	1
Providing informational resources & helping patients/family members evaluate and use resources	24	6	0
Facilitating assimilation, understanding, and recall of information	79	20	3
Fostering Healing Relationships	258	66	7
Discussion about roles and responsibilities	19	6	0
Honesty, openness, disclosure	35	11	1
Trust in clinician's technical competence, skills, and knowledge	51	13	0
Expression of caring and commitment	93	12	1
Building rapport, connection and respect	60	24	5
Managing Uncertainty	6	11	2
Constructing and defining uncertainty	0	2	0
Assessing and understanding uncertainty (cognitive)	0	1	1
Using emotion-focused management strategies (affective)	6	5	1
Using problem-focused management strategies (behavioral)	0	3	0
Recognizing and Responding to Emotions	27	35	0
Expression of emotions	11	12	0
Exploring and identifying emotions	5	3	0
Assessing depression, anxiety, or psychological distress	1	3	0
Acknowledgement and validation emotions	1	8	0
Expression of empathy, sympathy, and reassurance	5	7	0
Providing tangible help in dealing with emotions	4	2	0
Enabling Self-Management and Patient Navigation	38	32	1
Learning and assessing	5	3	0
Sharing and advising	11	12	0
Prioritizing and planning	2	2	0
Preparing, implementing, and assisting	14	12	0
Arranging and following up	5	3	0
Patient navigation	1	0	1
Making Decisions	189	60	4
Communication about decisional needs, decision support, and decision process	55	21	1
Preparation for the decision and deliberation	96	24	0
Making and implementing a decision and action plan	20	8	3
Assessing decision quality and reflecting on choice	18	7	0
Crosscutting Functions	107	41	0
Time for communication	24	8	0
Setting for communication	8	6	0
Communication about team roles and coordination	4	7	0
Basic interpersonal communication skills	71	20	0
Totals	983	314	19

Item Revision and New Item Development

In the final step, we adapted existing items (coded as “1” or “2” in the previous step) and developed new items to measure domains where gaps were identified. We developed guidelines for item revision and development, which we reviewed together with the candidate items at a working meeting with NCI and the expert advisors. The team agreed on the following guidelines for item development:

1. **Timeframe:** The majority of items will ask about the patient’s overall experience with cancer care (e.g., “Since you were first diagnosed with cancer...”). Selected items may reference a particular phase of care; for example, some items may ask about transition points in care or about making initial treatment decisions. The final survey should include a question(s) to determine the patient’s phase in the continuum of care. The initial focus for PCC assessment will be on patients who have been diagnosed and are in active treatment or post-treatment. Items could later be adapted for the diagnosis and end-of-life phases of care.
2. **Referent:** Items will ask about the patient’s “main doctor” rather than about the cancer care team. Many patients do not have, or perceive they have, a cancer care team. Also, patients may have very different communication experiences across multiple providers, making it challenging to respond to questions about the cancer care team. The final survey should include an explanation of “main doctor” (e.g., “the doctor who is in charge of your care”) and a question(s) to identify who the patient considers to be their main doctor (e.g., medical oncologist, surgeon, primary care doctor).
3. **Framing:** The final survey should include introductions to sets of items to frame the questions. Specifically, the introductions should help respondents understand the purpose of the questions, explain any terms as needed, and explain the time frame or other points the patients should reference in answering the questions. These introductions should also frame questions to minimize ceiling effects, for example by introducing the idea that not all physicians perform well on all of the communication tasks. The framing should give respondents permission to answer negatively.
4. **Response options:** The items will use a limited number of scales and response options. Most of the questions will be evaluative in nature and ask “to what extent” a communication behavior occurred (“not at all” to “very much”) or “how well” the doctor performed a behavior (“poor” to “excellent”). Some questions will ask “how often” a specific communication behavior occurred (never to always) and a limited number of factual questions will use the dichotomous yes/no response options.
5. **Pronouns:** Items will use “you” to refer to the patient and “your doctor” to refer to the patient’s doctor.
6. **Other considerations:** The goal is to develop four to six items per measurement domain. Items will be relevant for patients with different types of cancer and receiving care in different settings.

The project team agreed on several minor changes to the measurement domains to consolidate related constructs that had a great deal of overlap into single domains and make other adjustments (see Appendix I):

- *Fostering healing relationships:* We removed the subdomain “discussing preferences about receiving complete information” because it was adequately covered in the exchanging information function.

- *Managing uncertainty:* We combined the “assessing and understanding uncertainty” and “constructing and defining uncertainty” domains. The new combined domain is entitled “constructing, defining, and understanding uncertainty.”
- *Recognizing and responding to emotions:* We combined the “expression of emotions” and “exploring and identifying emotions” domains. The new combined domain is entitled “expressing, exploring, and identifying domains.” We renamed the “communication about roles and responsibilities of cancer team” and “discussion about roles and responsibilities” as “communication about cancer care team.”
- *Enabling self-management:* We added the “arranging and followup” domain and combined the “learning and assessing” and “sharing and advising” domains. The new combined domain is entitled “assessing, sharing, and advising.”
- *Cross cutting:* We will refer to this aspect of PCC as “crosscutting domains” rather than the “crosscutting function.” We differentiated between the “communication about team roles and coordination” domain in this function and the “discussion about roles and responsibilities” domain in the fostering healing relationships function and renamed the crosscutting domain “communication about cancer care team.”

The team also identified important issues to explore in the cognitive testing phase, including whether patients have any issues identifying their “main doctor,” whether they perceive any items as more or less relevant depending on their phase in care or cancer type, and whether they are able to understand nuanced distinctions among similar questions.

Question Appraisal System Review

An RTI survey methodologist who was separate from the project team and had not been involved in item development reviewed the items using the RTI Question Appraisal System (QAS).³ The QAS is a structured, standardized instrument review methodology that assists a survey design expert in evaluating questions relative to the tasks they require of respondents, specifically with regard to how respondents understand and respond to survey questions.⁴ In part, the QAS is a system that documents the question features that are likely to lead to response error. These potential errors include errors related to comprehension, task definition, information retrieval, judgment, and response generation. In particular, this QAS review focused on (1) reading requirements, (2) instructions and formatting, (3) clarity of the questions and response options, (4) knowledge/memory, and (5) response categories.

The QAS review found that most of the draft questions functioned well. The review also identified several issues to be addressed, including the following:

- **Complexity of questions:** Some questions were complex and had multiple components. The QAS reviewer advised simplifying questions where possible or dividing some questions into more than one question.
- **Order of response options:** For the questions asking “how well” the doctor performed a communication behavior, the response sets did not follow logically because the responses were presented from negative to positive (“poor” to “excellent”). The questions seem better suited to the response categories when the responses are reversed (i.e., positive to negative).
- **Stand-alone items:** Some items were broad and may be difficult to interpret if they stand alone (vs. reference or linked to other questions). For example, in some questions it was

unclear whether the respondent should answer in terms of their general health care or in the context of cancer treatment specifically.

- **Don't know/not applicable:** Some questions that appear to be subjective and all respondents should be able to answer included a “don't know” option. Some questions that may not apply to all respondents did not include a “not applicable” response option. The reviewer advised reviewing the questions to determine which ones require “don't know” and “not applicable” response options.
- **Use of “cancer” and “cancer care”:** Some questions specified “cancer care,” while others specified “cancer.” The reviewer advised reviewing the questions to determine if these terms are used consistently. It may be necessary to include an introduction that explains the distinction between questions that ask about cancer versus cancer care.
- **Use of parenthetical wording:** The use of parenthetical wording was not consistent and may be confusing to respondents. Also, the use of parenthetical worded contributed to the complexity of some questions. In some cases, parenthetical wording described an example, yet in other cases it was in addition to the preceding wording.

Item Set for Cognitive Testing

We revised items as appropriate based on QAS review with a focus on reducing complexity—as far as possible given the complex nature of some of the measurement domains and communication behaviors; standardizing the use of terms; clarifying broad questions; and ensuring that response options are appropriate for the questions. We formatted the revised items into a survey format for cognitive testing. We grouped the items into sets having a common topic and question stem, added introductions, and standardized the questions to use a limited number of response options (as above).

We developed cognitive testing instruments that included probes for exploring respondents' understanding of the instructions and items and how they select responses (see Appendix J).

Objective 3: Cognitive Testing of PCC Items^d

Introduction

RTI International conducted cognitive testing of draft patient-centered communication (PCC) items as part of Phase 2 of the Advancing Measurement of Patient-Centered Communication in Cancer Care project, a project sponsored by the National Cancer Institute (NCI) and the Agency for Healthcare Research and Quality (AHRQ) through AHRQ's Developing Evidence to Inform Decisions about Effectiveness (DEcIDE) I program. In Phase 1 of this project, we took steps to operationalize PCC by identifying measurement domains and subdomains for the following six functions of PCC framework:¹ (1) exchanging information, (2) fostering healing relationships, (3) recognizing and responding to emotions, (4) managing uncertainty, (5) making decisions, and (6) enabling patient self-management (see Figure 1).

The objectives of Phase 2 were to (1) refine and finalize the conceptual model of PCC; (2) develop measures for the key PCC constructs in the context of the PCC framework, including creating an inventory of existing measures and creating new candidate items; (3) conduct cognitive testing of candidate measures; and (4) create survey items for patients and guidance for a parallel survey for health care professionals. The survey items could be used in intervention research studies and for population-level surveillance. This report presents work conducted under Objective 3, Cognitive Testing of PCC Measures. The purpose of the cognitive testing was to assess whether the candidate items are understandable and adequately reflect the PCC functions and domains. In particular, the cognitive testing addressed (1) how well participants understood the questions, (2) participants' consistency in interpreting questions/response options, (3) participants' ability to recall necessary information, (4) appropriateness of questions, and (5) overlap among items.

We tested measures of PCC with patients who had a variety of types of cancer and who were in various stages of the cancer care continuum. We assessed the extent to which candidate measures are applicable and relevant across a range of clinical contexts, cancer types, and phases of cancer care.

In the subsequent sections, we present the cognitive testing methodology, findings that cut across multiple PCC functions and function-specific findings, and next steps in the instrument development process.

Methodology

We tested draft PCC survey questions using cognitive interviewing methodology with cancer patients in the Raleigh, NC, and Washington, DC, metropolitan areas. Participants were cancer patients who were recently diagnosed, were undergoing treatment, or had recently completed treatment. Participants were recruited by local market research firms and through local advertising and medical referrals.

Participants were screened over the telephone to increase the diversity of participants in terms of their phase of cancer care, type of cancer, educational level, sex, and race and ethnicity (see Appendix K for a copy of the recruitment screener). A total of 46 patients participated in the

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cognitive testing process, including 25 participants in Raleigh and 21 participants in the Washington, DC, metropolitan area. Table 4 provides an overview of participant characteristics.

Institutional Review Board Approval

All instruments used for recruitment and testing, including the recruitment screener, recruitment flyer, consent form, and interview guides, were reviewed and approved by RTI's Institutional Review Board.

Interview Procedures

Given the large number of survey questions to be tested (220 total questions), we divided the participants so that each participant tested only the questions for one function. The crosscutting and background questions were tested together with the questions about recognizing and responding to emotions and managing uncertainty, respectively (see Appendix M for copies of the questions tested for each PCC function).

Table 5 presents the distribution of cognitive testing participants by function.

Table 4. Participant characteristics

	Raleigh, NC	Bethesda, MD	Total
<i>Total Participants</i>	25	21	46
<i>Cancer Type</i>			
Breast	6 (24%)	8 (38%)	14 (30%)
Colorectal	—	—	—
Kidney/bladder	1 (4%)	1 (5%)	2 (4%)
Leukemia/lymphoma	2 (8%)	2 (10%)	4 (9%)
Lung	3 (12%)	2 (10%)	5 (11%)
Ovarian, uterine, cervical, endometrial	4 (16%)	2 (10%)	6 (13%)
Pancreatic	1 (4%)	1 (5%)	2 (4%)
Prostate	1 (4%)	2 (10%)	3 (7%)
Skin (melanoma)	1 (4%)	2 (10%)	3 (7%)
Skin (other)	1 (4%)	—	1 (2%)
Testicular	1 (4%)	—	1 (2%)
Other	5 (20%)	2 (10%)	7 (15%)
<i>Cancer Phase</i>			
Recent diagnosis	8 (32%)	3 (14%)	11 (24%)
Active treatment	10 (40%)	12 (57%)	22 (48%)
Posttreatment	7 (28%)	6 (29%)	13 (28%)
<i>Sex</i>			
Male	8 (32%)	6 (29%)	14 (30%)
Female	17 (68%)	15 (71%)	32 (70%)
<i>Education</i>			
Less than high school	—	2 (10%)	2 (4%)
High school graduate	5 (20%)	3 (14%)	8 (17%)
Some college	8 (32%)	4 (19%)	12 (26%)
Associate's degree	2 (8%)	7 (33%)	9 (20%)
Bachelor's degree	9 (36%)	3 (14%)	12 (26%)
Postgraduate degree	1 (4%)	2 (10%)	3 (7%)
<i>Ethnicity</i>			
Caucasian	17 (68%)	13 (62%)	30 (65%)
African American	7 (28%)	8 (38%)	15 (33%)
American Indian	—	—	—
Asian	1 (4%)	—	1 (2%)
Native Hawaiian	—	—	—

* Percentages may exceed total because some participants had more than one type of cancer.

Table 5. Distribution of participants and number of survey questions by function

Function	Number of Participants	Number of Questions
Exchanging information	9	40
Fostering healing relationships	8	37
Recognizing and responding to emotions (and cross-cutting)	7	28 (recognizing and responding to emotions) 14 (cross-cutting)
Managing uncertainty (and background)	7	21 (managing uncertainty) 11 (background)
Making decisions	8	37
Enabling self-management	7	32
Total	46	220

Trained RTI staff conducted the 90-minute, one-on-one cognitive testing interviews. Before each interview, the interviewer provided the respondent with a brief overview of the study and reviewed the informed consent document (see Appendix L for a copy of the informed consent document). Each participant was given a copy of the informed consent to keep for their records. The interviewer took notes during the interview and, with the participant's consent, we also audio-recorded the interview.

The interviewer first asked participants several background questions and then asked them to review the questions, reading the questions aloud and using the “think aloud” method as they responded to the questions.⁵ Participants received \$150 in appreciation of their participation.

Analysis

After the interviews, we entered findings into an analysis matrix for each PCC function, which organizes the findings by individual question and by participant. This approach allowed us to identify trends across participants and to develop recommendations (see Appendixes N through T for a summary of findings for each question).

Findings

The Cross-Function Findings section below summarizes general issues and recommendations that apply to multiple questions across one or more functions. In PCC Function-Specific Findings, we present key findings and recommendations specific to each PCC function. Detailed findings for individual survey questions are presented in Appendixes N through T.

Cross-Function Findings

We identified a number of issues that cut across multiple functions. These can be organized into two major categories—language and structural issues. Language issues have to do with the use of terms and concepts as well as other practical issues such as the reading-level requirements of the draft questions. Structural issues focus more on the mechanics of the questions such as the use of standard question stems and response scales, and question redundancy. In the following sections, we review these issues briefly and offer recommendations.

Reference to “Main Doctor” (Vs. “Team”)

In the cognitive testing, we asked participants whom they would identify as the provider primarily responsible for their cancer care and then instructed them to focus on this doctor when

answering the questions. In general, participants could readily identify their “main doctor.” Participants mentioned various factors when considering who their main doctor was, including the doctor who provides most of their care, makes decisions, coordinates their care (e.g., provides referrals), diagnosed the cancer, handles prescriptions and orders tests, provides documentation (e.g., for disability), is the specialist in their type of cancer, and is the doctor with whom they have the best relationship. Participants identified many types of doctors as their main doctor, including medical oncologists, gynecologists, urologists, gastroenterologists, and primary care providers. The type of doctor varied depending on the type of cancer (e.g., gynecologists/or gynecological oncologists for ovarian cancer, urologists for prostate cancer). Some participants said that their main doctor changed over the course of their care as the type of treatment they were getting changed (e.g., first surgeon and then radiation oncologist) or if they changed their place of care.

We explored whether it would make sense to ask participants about their “cancer care team” rather than (or in addition to) asking about their main doctor or other specific providers. Most participants had multiple providers involved in their care; however, in many cases they did not consider the providers to be a team. Participants perceived their providers to be a team based on considerations such as whether they shared information, were based in the same location, and met with each other (both formally and informally). Several participants said that their providers “worked well enough together” but still did not consider them to be a team.

Other participants had only a single doctor involved in their care and thus stated that asking about their cancer care team was irrelevant to their situation. Another issue with asking about the cancer care team is that participants’ experiences varied—often markedly—depending on the provider, so answering questions about the team as a whole would be very difficult.

We also explored whether participants thought the questions would apply to providers beyond their main doctor. Participants frequently mentioned that a nurse or another provider had provided information or support or played a key role in other aspects of PCC. In particular, participants thought many of the questions about exchanging information and fostering healing relationships were very relevant to nurses. As one participant explained, “Often the nurse is the one giving the information. You spend more time [with] and are more open with the nurse.”

Recommendation: We recommend maintaining “main doctor” as the referent for the questions, and including a brief set of questions in the survey instrument to identify the main doctor (e.g., specialist type) and the respondent’s relationship to the doctor (e.g., how long they have gone to that doctor, frequency of visits), as in the Background Q8 through Q11. If there is interest in assessing patients’ experiences with other providers, one approach would be for patients to select more than one provider and answer all (or selected) questions about each provider. For example, patients could identify the two to three providers most involved in their care or providers with whom they have the most and least positive experiences.

Questions About “Cancer” and “Cancer Care”

The cognitive testing explored participants’ understanding of questions that asked about “cancer” versus those that asked about “cancer care.” The findings varied regarding how well participants distinguished between such questions. In some cases, participants perceived a pair of questions as redundant (e.g., “How often do you and your doctor discuss...your feelings related to cancer” and “feelings related to cancer care?”) and, as a result, participants had difficulty distinguishing between them. However, in other instances, participants had no difficulty interpreting and responding to similar questions that asked about cancer and cancer care.

Problems with using these terms occurred particularly in the questions about recognizing and responding to emotions. It is possible that participants were responding in part to perceived overall redundancy in the recognizing and responding to emotions questions (see Recognizing and Responding to Emotions below).

Participants interpreted questions asking about cancer as referring to the disease or condition itself (e.g., type, stage, severity) and questions asking about cancer care as referring to clinical treatment and “the breadth of care.” One participant said that different emotions are associated with cancer and cancer care. Participants preferred “cancer care” over “cancer treatment” because cancer care was perceived as broader than just clinical treatment. Cancer care questions were also seen as encompassing social support and quality-of-life issues.

We asked whether repeating questions that focused alternately on cancer and cancer care created any confusion or was too repetitive. Of those probed on this issue, most said it was appropriate to ask parallel questions about both cancer and cancer care, although many participants felt that these questions were repetitive. However, it is important to note that outside a cognitive testing setting in which respondents are motivated to read the questions carefully, respondents may not perceive a distinction between questions asking about cancer versus those asking about cancer care.

Recommendation: We recommend reviewing the domains for which it is important to ask about both cancer and cancer care and, in some cases, deleting parallel questions. In addition, we recommend separating questions about cancer and cancer care into subsections with introductions to focus the respondents appropriately (e.g., “The following questions ask about your *cancer care*, such as the kinds of information you were given about your cancer care and your questions about your cancer care.”).

Relevance of Questions to Phases of Care

The questions appear to work well with patients who are in active treatment or who have recently completed treatment. Participants who had recently been diagnosed but had not begun their care, those who had been in treatment for a long time (e.g., successive rounds of treatment), and those who had finished treatment sometimes found it challenging to answer these questions. Some newly diagnosed participants had not yet made decisions, and some participants who had received cancer care over a long period of time or had completed treatment were unsure whether to answer questions in terms of their current experience or past care. They indicated that their answers would vary depending on the phase of care. For example, some of the questions about information exchange or making decisions—such as the discussion of options or how much the physician involved a patient’s family—were more relevant earlier in their care. Later in their care, they were on “automatic pilot” and did not need or want as much information exchange or decision support. Similarly, some of the questions that related to discussion with and about family (e.g., in fostering healing relationships and recognizing and responding to emotions) depended on the phase of care. Participants said that there was greater family involvement earlier in their care (e.g., family members were more likely to come with them for appointments). Later in treatment or in post-treatment, participants were less likely to discuss family issues and did not feel such discussions were as important.

These results suggest that patients perceive certain functions or domains as more or less relevant depending on their phase of care.

Recommendation: We recommend adding instructions stating that respondents should think about their *overall* cancer care experience (“since the time you were diagnosed with cancer”) when answering survey questions. The instructions should also acknowledge that some questions may be more applicable to different phases of their care. Some questions could refer to specific phases of care (e.g., “When you first started treatment...,” “After you were diagnosed...”), with a “does not apply” option for patients who have not experienced that phase of care.

For future iterations of the survey, developing modules for patients at different phases of care (e.g., newly diagnosed, active treatment, post-treatment) and focusing questions on their current phase of care may be desirable.

Questions Dealing With Culture and Background

Two of the draft questions asked about culture and background: “To what extent does your doctor ... discuss how your culture might affect how your cancer care is delivered?” (Self-Management Q20) and “To what extent does your doctor... show interest in your background and culture” (Fostering Healing Relationships Q13). Most participants seemed to understand the basic concepts of these questions and how their own or others’ backgrounds could potentially affect care. However, most participants said these questions were not relevant to their own experience with cancer care. Further, they said it was not important to them that doctors show interest in their culture and background.

However, two minority participants had a different view, saying that their background and culture did play a role in both their cancer and their cancer care. In addition, these respondents said they would answer the questions about background and culture differently.

Recommendation: Although these questions were found to be largely irrelevant to most cognitive testing participants, we believe that these (or similar) questions merit further testing, particularly with minority populations. In this set of interviews, primarily minority respondents indicated that culture or background played a role in their cancer care. Questions about background and culture might also be moved to the crosscutting questions. A brief introduction could frame the questions as follows: “These questions ask about any discussions you may have had with your doctor about your culture and your background. Culture refers to your language, customs, values, and your religious and other beliefs. Background refers to your personal and family background, such as where you live and who is in your family.”

Understanding Medical Terms and Other Literacy Issues

Medical terms were used primarily in the background questions that ask about the patient’s diagnosis and treatment. Note that we developed and tested these background questions to provide context for the PCC questions; however, background questions were not part of the scope of work and, thus, were not a focus of the analysis. Briefly, some participants were unfamiliar with treatment-related terms such as “complementary and alternative medicine” and “targeted, biologic, and immune therapies.” However, participants were generally able to answer these questions because they were familiar with the terms that related to their own type of cancer and cancer care. One participant with less than a high school education had difficulty with these terms and with understanding a number of the questions more generally; this participant also had difficulty with the consent form, background questions, and other survey questions. The other lower education participants were able to understand and respond to the survey questions, although they often had to read questions multiple times before providing an answer.

Recommendation: The specific problems and recommended solutions for problematic questions are highlighted in the function-specific findings, as appropriate (see PCC Function-Specific Findings).

Questions About “Family or Caregivers”

A number of questions ask about “family or caregivers,” with parallel questions in many functions (e.g., the making decisions function includes questions about extent of discussions with the doctor about *their own* involvement and *their family or caregiver’s* involvement in decision making). The cognitive testing revealed several issues with asking about caregivers. First, participants’ interpretation of “caregivers” varied quite a bit. Some participants understood caregivers to mean professionals, including health professionals and social workers. Others understood the term to mean family, friends, and nonprofessionals. For example, one participant said it could be “anyone who spends a lot of time with you in the process, like a spouse or someone else.” In response to a question about discussing “what is important to your family or caregivers when planning your cancer care,” a few participants said they would answer differently for family and caregiver.

In some cases, participants did not perceive questions about family or caregivers as relevant to their situation because they did not expect or want family members involved in their care. Family involvement was not feasible given their circumstances (e.g., due to distance from family) for some other participants. Also, some participants considered the questions about family to be more or less relevant depending on the phase of care (see further discussion of this issue in Relevance of Questions to Phases of Care). For example, one participant said that because she was then in the post-treatment phase, her family was no longer involved in any of her care, so some questions were not relevant.

Recommendation: We recommend revising these questions to ask about family only (not caregivers) and to provide a broad and inclusive definition of family (e.g., inclusive of extended family, significant others/individuals who are viewed as or act in the role of family members). Also, we recommend continuing to offer the “does not apply” option so that respondents for whom family is not relevant know to select this option. In terms of the phase-of-care concern, see recommendations in Relevance of Questions to Phases of Care.

Question Stems

In general, the question stems worked as intended. According to participants, in most cases the stems fit well with the concepts addressed in the questions. However, in a number of cases participants lost track of the stem in long blocks of items or simply missed the change from one stem to another as they moved to a new set of questions. For example, in questions that ask, “To what extent do you and your doctor discuss...” or “To what extent does your doctor discuss...,” participants ignored “discuss” in the stem. For example, in fostering healing relationships Q14 (“To what extent do you and your doctor discuss how you will work together as a team during your cancer care?”), some respondents ignored the stem and answered in terms of the extent to which they worked as a team with their doctor rather than the extent to which they *discussed* working as a team with their doctor.

Recommendation: A variety of formatting steps can be taken to draw respondents’ attention to question stems: adding instructions that include a reminder to pay attention to the stem; using visual cues such as color, bolding, or arrows to draw attention to the stem; providing an example

of the question and stem each time the question stem and associated response options change; or using a combination of the above methods. We recommend using bold text and instructions to draw participants' attention to the use of stems. In addition, for question stems that include "discuss" (e.g., "To what extent do you and your doctor discuss..."). We also recommend moving "discuss" to the body of the question. These revisions would highlight the use of stems without increasing the reading burden on participants, which would occur with adding example questions.

In addition, some questions could potentially be converted to use dichotomous (yes/no) response options to reduce the respondent burden. However, we recommend that this approach be used on a very limited basis because it provides less information. The yes/no response tells us only whether a communication behavior occurred but not how often, how well, or to what extent the behavior occurred.

Recommendation: Table 6 indicates examples of items that could potentially be revised to use the yes/no response options, or in some cases, a different five-item stem. These are for consideration only, and we recommend making this change to only a small number of items.

Table 6. Items for potential revision

Function	Items
Exchanging information	9–15
Fostering healing relationships	21–22
Recognizing and responding to emotions	7–10
Managing uncertainty	1a–1t (likely to work better as yes/no vs. check if apply)
Making decisions	15–18, 24–29
Enabling self-management	18–20
Cross-cutting	1–14

Response Scales

The response scales appeared to work well with participants. Although a small number of participants suggested some slight changes to the words used for the response options, the majority indicated that the response options were clear and appropriately ordered, and they matched the questions being asked. Most of the suggested changes appeared to represent idiosyncratic preferences. For instance, one participant suggested changing the response option "very much" (from questions that used "to what extent") to "a bunch."

Participants generally appeared to use the full range of response options in providing answers to the questions, suggesting that floor and ceiling effects may not be a major issue with the PCC items. Their explanation about how they chose answers corresponded well with the answers chosen. These results suggest that the use of the "to what extent" stem for the majority of questions had the intended effect of allowing participants to choose a range of responses and not simply select all positive or negative responses. However, as noted earlier, respondents outside a cognitive testing setting may not read the questions and response options as carefully, and thus their responses could be distributed differently.

In a small number of cases, participants pointed out what they perceived as mismatches between the question and the response scale. Participants could understand and respond to these questions but felt the questions would be easier to answer with a better match between the question and response options.

Recommendation: We recommend making some minor revisions to some questions so that they are more compatible with the response options.

Question Redundancy

The draft survey questions intentionally included some redundancy so that we could test different ways of wording a question or asking the question with different stems (e.g., “how well” and “to what extent”). For example, several questions in fostering healing relationships ask about the doctor’s demonstration of interest in them as an individual: “To what extent does the doctor... show that he or she cares about you as an individual person,” “show real interest in you as an individual person, not just your illness,” “treat you as an individual,” “treat you as a person, not just another patient,” and “try to get to know you as an individual person.”

In some cases, participants perceived questions as redundant when in fact the questions were intended to reflect fine distinctions between related concepts. However, these distinctions appear to be largely lost on participants who simply saw questions as redundant (e.g., “To what extent did you and your doctor discuss... how you *could* be involved in your cancer care?” and “To what extent did you and your doctor discuss... how you *would like* to be involved in your cancer care?”). In another example, many participants did not see the distinction between “How often does your doctor... help you understand the information you need to know about your cancer?” and “How often does your doctor... make sure you understand important information about your cancer?” In general, some of the nuanced differences in concepts that are important from a theoretical perspective may not be perceived as distinct or important from the patients’ perspective.

Recommendation: We recommend dropping questions that are clearly redundant if the cognitive testing demonstrated that participants understand or prefer one question more than another. Otherwise, we recommend retaining questions or modifying questions as needed to clarify fine distinctions in the concepts measured. Ideally, final decisions about cutting such questions would be based on future field testing of these questions.

PCC Function-Specific Findings

The following sections provide findings and recommendations specific to each function.

Exchanging Information

Overall, the exchanging information questions were well understood and easy to answer. However, participants noted that some questions were more relevant to early stages of their cancer care and less relevant later (e.g., Q1, Q2, Q32, and Q33). Specific findings and recommendations are discussed below.

Questions 1 through 8 ask to what extent the patient and doctor discuss the patient’s concerns and questions, how much information the patient needs, and differences of opinion or beliefs.

Two questions (Q1 and Q2) were more relevant to patients in early treatment and not as relevant at later stages of cancer care.

Q7 and Q8 (“To what extent do you and your doctor discuss...any differences of opinions or beliefs about your cancer/cancer care?”) were confusing for a number of participants, because they were not sure whether the differences of opinion referred to in the question were between doctors or between the doctor and the patient. Since participants also often trust their doctor to be right, this inhibits their awareness of

differences of opinion.

Recommendation: We recommend dropping Q7 and Q8.

Questions 9 through 15 ask to what extent the doctor shows an interest in the patient's experience, makes the patient feel comfortable asking questions and sharing information, and listens carefully to the patient.

There were no problems in responding to Q10 regarding the extent to which their doctor asks them to share their "cancer experience." Participants understood this term to refer to their "entire experience with care," "total life," and "both physical and emotional aspects of having cancer." A number of participants, however, indicated their doctor does not directly ask about their cancer experience, but that they believe their doctor knows about and understands their experience.

In response to Q15 ("To what extent does your doctor check to be sure he or she understands what you say?"), some participants noted that the idea that their doctor would check their understanding of what the patient says sounded strange, and they thought it was not necessary for a doctor to do this. Others misunderstood the question to be asking if doctors checked to be sure the patient understood what the doctor said.

Recommendation: We recommend dropping Q15.

Questions 16 through 31 ask how often the doctor gives them information and materials, explains information, and checks for understanding.

Participants perceived Q20 ("How often does your doctor... give you brochures, written information, or other materials to help you remember important information?") and Q21 ("How often does your doctor... give you materials—e.g., brochures, DVDs or videos, web sites—that are helpful to you?") as redundant. Also, participants said that their doctor does not usually *give* them materials, but instead makes them aware of available materials. Others said it was generally the nurse who gave or told them about materials. Also, participants thought DVDs and videos were not commonly used and should not be included as examples of materials.

Recommendation: We recommend dropping Q 20 and rewording Q21: "How often does your doctor... give you *or tell you about* brochures, written information, or other materials that are helpful to you?"

Some participants felt that Q24 ("How often does your doctor... explain information in different ways to help you understand?") was clear and useful, whereas others felt that it would involve the doctor "talking down" to them (e.g., "sounds like patient is dumb and doesn't get it the first time," "refers to having to talk to you like a child").

Recommendation: We recommend dropping Q24.

Participants noted a redundancy between Q25 ("How often does your doctor... help you understand the information you need to know about your cancer?") and Q27 ("How often does your doctor... make sure you understand important information about your cancer?"), as well as between Q26 ("How often does your doctor... help you understand the information you need to know about your cancer care?") and Q28 ("How often does your doctor... make sure you understand important information about your cancer care?"). Participants did not perceive a difference between "helping" them understand

and “making sure” they understand.

Recommendation: We recommend dropping Q27 and Q28.

Questions 32 through 35 ask to what extent the doctor checks to see what kinds of information the patient wants and discusses information obtained from outside sources.

Q32 (“To what extent does your doctor... check to see what kinds of information you would like to have about your cancer?”) and Q33 (“To what extent does your doctor... check to see what kinds of information you would like to have about your cancer care?”) were clear and easy to answer, but participants noted that these questions were more relevant to patients in early treatment than to patients in later stages of care.

Participants did not have any difficulty understanding Q34 (“To what extent does your doctor... understand what kinds of materials—e.g., brochures, DVDs or videos, web sites—might be helpful for you?”) but indicated that it is problematic to ask them what their doctor “understands” because there is no way to know this without discussing it. They also thought this topic was redundant with Q20 and Q21.

Recommendation: We recommend dropping Q34.

Questions 36 through 38 ask about sharing difficult news. The introduction to this section is: “Sometimes, doctors have to share difficult (or “bad”) news with cancer patients.”

Most participants thought that the terms “difficult” and “bad” were interchangeable. However, a few thought “bad” implied something worse than “difficult.” Generally participants thought it was helpful to use both terms in the introduction.

In response to Q36 (“Has your doctor ever had to share any bad news with you about your cancer care?”), one participant questioned the focus on cancer care instead of cancer in general.

Recommendation: We recommend revising to “Has your doctor ever had to share any bad news with you about your cancer?”

Questions 39 and 40 ask how well the doctor does with sharing bad news.

Participants interpreted Q39 (“How well does your doctor share bad news... in the way that is right for you?”) in various ways, and several thought it sounded strange and was unclear. Interpretations of “right for you” included the setting (e.g., in person or on the telephone), considers “how I like to receive news,” whether doctor was rushed, and how sensitive the doctor was.

Recommendation: We recommend dropping this question.

Fostering Healing Relationships

Overall, participants thought the questions in this function asked about important aspects of their relationships with their doctors. In this section, we discuss specific findings and recommendations.

Questions 1 through 13 ask to what extent the doctor treats a patient as an individual, shows caring and commitment, and shows interest in the patient’s background and culture.

Participants found most of these questions clear and easy to answer, although they noted redundancy across some of the questions, especially the questions about whether the

doctor treats them as an individual (Q1, Q2, Q3, Q6, Q7). All of these questions performed well, and there were no consistent preferences for one question over another.

Recommendation: We recommend dropping one or more of these questions. Although the cognitive testing findings do not provide clear evidence for recommending one question over the other, we suggest dropping Q9 (“To what extent does your doctor... show that he or she cares about your family?”) because of the finding that patients consider attention to family as a somewhat lower priority (see Questions About “Family or Caregivers”). We also suggest dropping Q6 (“To what extent does your doctor... treat you as an individual?”) because of the overlap with Q7, which is more detailed (“To what extent does your doctor... treat you as a person, not just another patient?”).

Q11 asks whether the doctor shows “commitment to your cancer care.” Participants’ interpretation of commitment to care varied (e.g., “being there,” responsive, taking care of what needs to be done, caring), and none mentioned commitment to ongoing care or nonabandonment.

Recommendation: If there is interest in capturing this subdomain, we recommend adding a question to ask specifically about respondents’ perceptions of the doctor’s commitment to their ongoing care.

Q13 asks “To what extent the doctor... shows interest in your background and culture?”

Recommendation: We recommend further testing of questions related to culture and background (as discussed in Questions Dealing With Culture and Background).

Questions 14 through 20 ask to what extent patients discussed roles with the doctor and what the patient’s and family/caregiver’s involvement in cancer care with the doctor was.

Several participants ignored the question stem—“To what extent do you and your doctor discuss...”—and were confused by the question (Q15) or answered in terms of their preferences for involvement (Q16 through Q18) or for family involvement (Q19 through 20) rather than whether they *discussed* these preferences with their doctor.

Recommendation: As discussed in Question Stems, use formatting techniques to highlight the stem.

Participants had difficulty differentiating questions that asked about how they “would like to be involved” (Q16) and how they “could be involved” (Q17) in their cancer care; similarly, they had difficulty differentiating questions about how their family/caregiver “would like to” versus “could be” involved.

Recommendation: Although these questions were intended to measure distinct constructs, participants were unable to grasp the difference. As a result, we recommend dropping Q17 (“To what extent did you and your doctor discuss how you could be involved in your cancer care?”) and Q20 (“To what extent did you and your doctor discuss how your family [or caregivers] could be involved in your cancer care?”).

Questions 21 through 27 ask about openness and honesty in communication and whether the doctor shares information in a way patients prefer.

Several participants had difficulty with Q21 (“To what extent do you and your doctor... discuss the importance of open and honest communication?”) because they felt openness and honesty were assumed and did not need to be discussed.

Recommendation: We recommend revising to “To what extent does your doctor encourage you to share information openly and honestly?”

Some participants also had difficulty with Q22 (“To what extent do you and your doctor... have open and honest communication, including differences of opinion?”) because they had not experienced differences of opinion, yet felt they had open and honest communication.

Recommendation: We recommend deleting “differences of opinion” in this question so that question reads: “To what extent do you and your doctor have open and honest communication?” A separate question could ask specifically about differences of opinion: “To what extent do you and your doctor discuss any differences of opinion openly and honestly?” (Participants could select “NA” if they have not experienced differences of opinion.)

Some participants had difficulty understanding Q24 (“To what extent do you and your doctor... share information in a way that you prefer?”) and Q26 (“To what extent do you and your doctor... share information with your family (or caregiver) in a way that you prefer?”). They were unsure how to interpret “in a way that you prefer,” and several participants ignored this phrase.

Recommendation: We recommend dropping Q24 and Q26.

Questions 28 through 32 ask about communication related to trust and confidence. Participants found all of these questions easy to understand and to answer.

The only concern was redundancy between Q30 (“To what extent does your doctor talk to you in a way that makes you... feel confident in his or her ability to meet your cancer care needs?”) and Q31 (“To what extent does your doctor talk to you in a way that makes you... trust in her or her ability to provide you with the care you need?”). There was no preference for either question.

Recommendation: We recommend dropping Q30 because it is more complex. Consider rewording Q31 to use a different stem.

Questions 33 and 34 ask about the doctor’s communication with other health care providers.

These questions overlap with items in the crosscutting domains (Crosscutting Q13 and Q14).

Recommendation: We recommend moving questions to the crosscutting domains (see discussion of these and related questions in Crosscutting).

Questions 35 through 35b ask about communication about any medical mistakes or errors. This situation is likely to be rare, so for a surveillance survey, these questions may not be appropriate.

Generally participants understood the terms “medical mistakes or errors,” although one was unsure about including hospital-acquired infections and another about “minor” errors.

Recommendation: We recommend adding a user-friendly definition of medical mistakes or errors.

Several participants missed the skip instructions and tried to answer Q35a (“Did your doctor discuss the medical mistakes or errors with you?”) and Q35b (“How well did your

discuss the medical mistakes or errors with you?”), even though they had not experienced any medical mistakes or errors.

Recommendation: We recommend highlighting the skip instructions (e.g., formatting changes or other visual cues) to draw participants’ attention to them.

Recognizing and Responding to Emotions

Overall, participants perceived the questions about recognizing and responding to emotions as clear and addressing important aspects of cancer care. Participants noted some redundancy across questions in this function. Participants also consistently noted that the questions about involvement of family or caregivers (e.g., Q12, Q16, Q27) were relevant to the early stages of cancer care but were not relevant in later stages.

In addition, some participants were confused about the meaning of “cancer care” in the context of this PCC function. Specifically, they had difficulty making a distinction between some of the questions that asked about cancer versus those asked about cancer care. When probed, participants initially identified a difference between cancer and cancer care, but there was quite a bit of variation in definitions. For example, one participant thought that Q5 (which asked about cancer care) was the same as Q4 (which asked about cancer). Also three participants thought Q25 (“To what extent does your doctor help you think about ways to deal with stress related to cancer care?”) was the same as Q24 (“To what extent does your doctor help you think about ways to deal with stress related to cancer?”). (See additional discussion of these terms in Questions About “Cancer” and “Cancer Care.”)

Additional specific findings and recommendations are discussed in the following paragraphs:

Questions 1 through 6 ask about the frequency of communication between the doctor and patient about coping and feelings related to cancer and cancer care.

Regarding Q1 and Q2 (“How often do you and your doctor discuss... how you are coping with your cancer/cancer care?”), most participants agreed that adding “coping *emotionally*” made the question clearer because, as one participant pointed out, “there are a lot of things you could cope with.”

Recommendation: We recommend revising Q1 and Q2 to “How often do you and your doctor discuss... how you are coping *emotionally* with your cancer/cancer care?”

Questions 7 through 28 ask to what extent the doctor shows awareness of and concern for the patient’s feelings and helps the patient cope with his or her feelings.

Participants had no problem with the phrase “seem to know,” which was included in Q8 through Q10 (e.g., “seem to know if you are feeling sad and blue”). They generally thought the phrase made sense and was clear.

Recommendation: No change recommended in the use of “seem to know.”

Several participants felt that Q9 (“To what extent does your doctor... seem to know how you are coping with your cancer?”) was repetitive; one participant thought it was the same as Q8 (“To what extent does your doctor... seem to know if you are feeling sad or blue?”).

Recommendation: We recommend retaining both questions because they performed well and Q9 addresses a broader issue. In addition, Q8 deals with symptoms of depression more directly.

Participants also noted that Q10 (“To what extent does your doctor... seem to know how you are coping with your cancer care?”) was redundant and that it was similar to Q8 and Q9. One participant interpreted Q10 as asking about the extent to which the doctor seems to know how the patient is *physically* coping with his or her cancer care program, rather than how he or she is *emotionally* coping.

Recommendation: We recommend dropping Q10 because it is implicitly covered by Q1 and Q2.

Several participants thought that Q15 (“To what extent does your doctor... show concern about how you are doing emotionally?”) was the same as Q14 (“To what extent does your doctor... show concern for your feelings, not just your illness?”). There was no preference for one question over another.

Recommendation: No changes are recommended.

One participant noted that Q16 (“To what extent does your doctor... show concern for how your family or caregiver is doing emotionally?”) was very similar to Q12 (“To what extent does your doctor... show that he or she is aware of your family's or caregiver's feelings?”).

Recommendation: We recommend dropping Q12 because awareness is encompassed in “show concern.”

In response to Q21 (“To what extent does your doctor... comfort and reassure you?”), several participants indicated that this occurred not through direct communication but by simply seeing the doctor or by knowing they can contact the doctor whenever necessary.

Recommendation: No changes are recommended.

Several participants responded negatively to Q22 (“To what extent does your doctor... show that he or she understands what it feels like to be in your situation?”). They indicated that this question was not relevant or applicable because the doctor could not know or truly understand what it was like to be in their situation because the doctor had not experienced it. These and other participants, therefore, answered the question in terms of whether the doctor showed that he or she understood their experience.

Recommendation: We recommend dropping Q22.

In response to Q23 (“To what extent does your doctor... give you emotional support?”), several participants indicated that the doctor did not provide emotional support directly but that he or she delegated the provision of emotional support to other professionals (e.g., through referral to a psychiatrist or psychologist) or that doctors provided emotional support simply by spending time talking with the patient.

Recommendation: No changes are recommended; consider adding a question about whether the doctor ensures that the patient gets emotional support from other sources.

Several participants thought Q27 (“To what extent does your doctor... help you plan to get help—e.g., counseling, support groups, medications—to better cope with your emotions?”) was redundant. They noted that it was the same as Q24 (“To what extent does your doctor... help you think about ways to deal with stress related to cancer?”) and Q26 (“To what extent does your doctor... tell you about support groups or treatments that could help you deal with your emotions related to cancer and cancer care?”). Participants also interpreted and responded to Q27 the same way as Q26.

Recommendation: We recommend dropping Q27 because the wording is more complex (“help you plan to get help”) than the wording in Q24 and Q26.

Most participants viewed Q28 (“To what extent does your doctor... suggest things you can do to cope with your concerns and fears about cancer?”) as being redundant with Q24 (“To what extent does your doctor... help you think about ways to deal with stress related to cancer?”).

Recommendation: We recommend dropping Q28 because it is narrower than Q24, which covers cancer-related stress more generally.

Managing Uncertainty

The cognitive testing identified a number of challenges with the managing uncertainty questions. We anticipated assessment challenges because of the complexity of the constructs and because limited previous efforts have assessed this aspect of PCC. The lack of existing research in this area was reflected in the question inventory; we identified the fewest existing candidate questions for the managing uncertainty function (n=13).

The introduction to the managing uncertainty questions frames the questions as follows: *During medical care, there may be situations where there is not a clear answer or where doctors and patients don't know the answer to an important question. For example, experts sometimes disagree about which treatment is best, or doctors cannot be sure which side effects will occur during treatment. These types of situations can cause uncertainty for patients.* Although most participants seemed to understand the introduction and the concept of uncertainty in cancer care, many had difficulty interpreting uncertainty in the context of specific questions.

Given the significant issues with the managing uncertainty questions, we do not present findings and recommendations for individual questions as we did for other functions. Instead, we discuss general findings and issues and then present several options for revising and restructuring the managing uncertainty questions. Detailed findings for each question are presented in Appendix Q.

Participants perceived different types of uncertainty—scientific uncertainty (e.g., “There are some things nobody knows”) and patient uncertainty (e.g., “There are things I don't know but my doctor knows. And there are things that I think I know, but I'm going to ask my doctor just to be sure.”). Participants also said there were uncertainties that were not very important to them or not distressing. Participants seemed to have difficulty thinking about all these types of uncertainties and knowing which ones to consider in the context of different questions.

Q1 (through Q1T) was intended to set the stage by asking participants to think about the types of uncertainties they had experienced over the course of their cancer care. The question lists a wide range of uncertainties (e.g., uncertainty about prognosis, treatment choices, where to go for treatment, health insurance coverage). Respondents understood most of the types of uncertainties listed and also suggested several additions (see Appendix Q for details). However, some participants checked a particular type of uncertainty, but said it was not important to them, did not cause distress, or was easily clarified. Another issue was that some participants checked a type of uncertainty because they had discussed the topic with their doctor, not because they experienced it as an uncertainty.

Some participants did not know what was meant by “sources of uncertainty” (e.g., Q5, which asks, “How well does your doctor... identify possible sources of uncertainty in your cancer care?”). “Reasons for uncertainty” was better understood, although a few participants had difficulty with this terminology as well (e.g., Q6).

The questions that ask about uncertainties caused by experts not having enough information (Q9) or having different opinions (Q10, Q11) were very difficult for participants. For example, Q11 asks “How well does your doctor... help you understand why experts have different opinions about your type of cancer care.” Some participants could not process this scenario. They first had to recall an uncertainty caused by different opinions and then recall how well their doctor explained it. Cognitively, this seemed too demanding for some participants.

A few participants said that discussion about uncertainties occurred mostly at the time of diagnosis or when making treatment decisions and less so at other points in their cancer care. Because the frequency of these discussions varied, they had difficulty with questions about how often they discussed uncertainties (Q3) or discussed their questions about the uncertainties (Q4) with their doctor.

Participants thought some questions were not relevant to their situation, because they had not experienced uncertainties (Q7, Q8) or not experienced certain types of uncertainties (e.g., experts having different opinions) (Q11).

Recommendations:

We offer several possible approaches to revising the managing uncertainty questions to address the identified issues:

Option 1. Revise Q1, which sets the stage for subsequent questions. A two-part question could ask (1) whether patients have experienced different types of uncertainty, and (2) of the uncertainties patients have experienced, which were of concern to them or caused anxiety/stress. For subsequent questions, patients should be instructed to think only about the types of uncertainties that caused anxiety or stress. The limitation of this option is that it may skip out a sizeable proportion of respondents. Another option would be to drill down on each type of uncertainty that participants identify as causing concern and ask whether they discussed the uncertainty with the doctor and whether/how the discussion was helpful in terms of understanding and coping with the uncertainty, for example. This option would be more feasible with a Web-based survey than with a paper-and-pencil survey.

Option 2. Seek ways to categorize different types of uncertainty and ask about each type separately. The taxonomy of uncertainty developed by Han and colleagues (2010)⁶ can be helpful in thinking about ways to categorize items in the managing uncertainty function. This taxonomy specifies two dimensions of uncertainty: sources (or type) of uncertainty and issues (or domain) of uncertainty.

Sources of uncertainty:

probability of something occurring (e.g., positive outcome of treatment), in which uncertainty pertains to the indeterminacy of future outcomes;

ambiguity, which occurs when there is expert disagreement or insufficient scientific evidence; and

complexity of the phenomena (e.g. probabilities of different outcomes vary according to multiple factors).

Issues of uncertainty:

scientific uncertainty (lack of evidence, conflicting evidence, experts disagree), which could potentially apply to scientific uncertainty about the diagnosis, prognosis, causal explanations, and treatment recommendations;

practical uncertainty, which applies to the structures and processes of care, including uncertainty about the competence of one's physician, the quality of care one can expect to receive, or the responsibility and procedures one must undertake to access care; and

personal uncertainty, which pertains to psychosocial and existential issues including the effects of one's illness or treatment on one's goals or outlook on life, on one's personal relationships, the welfare of loved ones, or one's sense of meaning in life.

Items could be grouped by categories of uncertainty with an introduction describing the category and some illustrative examples. A screener question could assess whether the participant has experienced this category of uncertainty. If they have, subsequent questions would ask about discussions with the doctor, how well the doctor explained the uncertainty, and whether the doctor helped in coping.

Option 3. Another option would be to eliminate managing uncertainty as a unique function and move some of the better-performing questions to other functions, particularly exchanging information and recognizing and responding to emotions. In addition, some questions could be added to the other functions focusing on relevant aspects of uncertainty. Such items would often be context-specific, however, and thus might not apply to all respondents. For example:

One or more of the questions about whether the doctor informed the patient about and discussed uncertainties (Q2, Q3, Q4) and explained uncertainty (Q5 through Q11) could be included in exchanging information.

One or more of the questions about how the doctor responded to emotions and feelings about uncertainty (Q12), helped with coping (Q14), and provided comfort and reassurance about uncertainty (Q18) could be moved to recognizing and responding to emotions.

Additional items about uncertainty related to making decisions, for example, focusing on uncertainty about risks and benefits and outcomes of different choices. Add items about uncertainty related to self-management, for example uncertainties about the cancer care plan and what will happen next.

A disadvantage of this approach is that the concept of uncertainty would have to be introduced at more than one point in the survey. However, it is possible that the questions could be revised to avoid use of the term "uncertainty" (a high literacy-level term) and instead use wording such as "things you are unsure about."

Making Decisions

One general issue with these questions was that some participants said they had not had any choices in their care (e.g., there was only one treatment option) so they did not perceive that decisions were made. As a result, they were unclear how to answer some of the questions and did not seem to consider choosing the "does not apply" response option. Participants may be more likely to select "does not apply" if completing the survey on their own; in the cognitive testing

setting, participants may try to select an answer to be helpful to the researcher.^{7,8} It also appeared that patients interpreted the questions to refer only to “big” decisions, for example, decisions about distinct treatment choices (e.g., surgery vs. chemotherapy) and did not consider other types of decisions (e.g., watchful waiting, timing or location for treatments, options for dealing with side effects). We recommend revising the introduction to clarify that the questions apply to different types of decisions.

We discuss additional specific findings and recommendations in the following paragraphs:

Questions 1 through 8 ask *to what extent* the doctor and patient discuss preferences for involvement in decision making, considerations in making decisions, and the doctor’s recommendation.

Q3 and Q4 probed reactions to “what matters most to you (or to family/caregiver)” versus “what is important to you (or to family/caregiver)” in making decisions about cancer care. Respondents understood the two versions to mean the same thing, and there was some preference for “what is important to you.”

Recommendation: We recommend revising the questions to use “what is important to you.”

Q6 and Q7, which ask “how different treatment choices would affect you (or family/caregiver),” were problematic for some participants because, as noted previously, they did not have treatment choices. In addition, some participants thought what matters most to “family or caregivers” (Q7) was not a priority topic for discussion with their doctor.

Recommendation: We recommend dropping Q7 because attention to effects on family is a lower priority.

Questions 9 through 18 ask *to what extent* the doctor makes it clear when there are decisions to be made, explains the choices, and shares information to help in making decisions.

In Q9, we probed understanding and preference for “make it clear there are decisions to be made” versus “decisions to make.” There was some preference for “decisions to make.”

Recommendation: We recommend revising to “decisions to make.”

Some participants had difficulty with Q10 (“explain the different choices in your care”) because they did not have (or did not perceive they had) any choices.

Recommendation: As stated previously, we recommend revising the introduction.

Most participants interpreted Q11 (“explain the advantages and disadvantages”) and Q12 (“explain the risks and benefits”) to mean the same thing. There was some preference for Q12.

Recommendation: We recommend dropping Q11.

In Q16, we probed “things to think about that help you make decisions” versus “things to consider.” There was preference for “things to consider.”

Recommendation: We recommend revising to “things to consider.”

Q18 asks whether the doctor shares materials to help make decisions. Two participants found the parenthetical examples of materials in the middle of the sentence difficult to

follow.

Recommendation: We recommend moving the parenthetical examples to the end.

Questions 19 through 23 ask how well the doctor answers questions and explains different choices and his/her recommendation.

Some participants had difficulty with Q19 (“explain the different choices in your care”) because they did not have (or perceive they had) any choices.

Recommendation: As stated previously, we recommend revising the introduction.

Most participants interpreted Q21 (“explain the advantages and disadvantages”) and Q22 (“explain the risks and benefits”) to be redundant with other questions (Q11 and Q12 ask *to what extent* the doctor did these things). Also, they thought the questions did not need to specify “before making decisions about your care” because that could be assumed.

There was some preference for Q22.

Recommendation: We recommend dropping Q21.

Questions 24 through 32 ask about discussions after making decisions.

Q26 and Q27 ask to what extent the doctor checked for understanding about “what the decision will mean for you” (or for your family/caregiver). Q30 and Q31 ask to what extent patients and their doctor discuss “what the decision will mean for you” (or your family/caregiver). Several participants were unsure how to interpret “what the decision will mean,” (e.g., whether it referred to effectiveness, side effects, or “existential meaning”).

Recommendation: We recommend dropping Q26, Q27, Q30, and Q31.

Q32 asks whether they discussed any possible problems carrying out the decision. Most participants found this question confusing and/or not relevant; several said it did not make sense because they did not need to do much to carry out the decision (e.g., “simply had to show up,” for example, for surgery or radiation). They thought it would be relevant if they had to do things on their own.

Recommendation: We recommend dropping Q32.

Questions 33 through 37 ask about patients’ discussions with their doctor after they have carried out decisions.

Q36 asks to what extent they discussed any problems they had carrying out the decision. As noted for Q32, some participants thought this question was not relevant because the decision did not require them to do anything on their own.

Recommendation: We recommend dropping Q36.

Q37 asks to what extent they discussed making any changes to the decision. Several participants said the question was not relevant because they did not have options.

Recommendation: We recommend dropping Q37.

Enabling Self-Management

The introduction to the enabling self-management questions frames the questions as follows: These questions focus on how you and your doctor talk about managing your cancer, your treatment, and your health, especially between visits to the doctor.

A number of the questions asked about “family and caregivers” (Q3, Q4, Q6, Q11, Q14). As discussed previously, we recommend providing a definition of family and deleting the reference to caregivers (see further discussion of this issue in Questions About “Family or Caregivers”). To illustrate the need to define family, one participant excluded his wife in response to a question about discussion of how cancer is affecting the family’s everyday life (Q3) because his wife is part of the health care visit. He interpreted the question as referring to other family members.

The term “cancer care plan,” used in a number of questions (Q8, Q12, Q13, Q14), was confusing to some participants and was interpreted in a variety of ways. We recommend revising the wording to “plans for your cancer care.”

Other specific findings and recommendations are discussed below:

Questions 1 through 14 ask about discussions with the doctor about how cancer is affecting their life, preferences and what is important to them in planning their cancer care, and discussions about their cancer care plan.

Q1 asks “To what extent do you and your doctor discuss... how cancer is affecting your everyday life” and Q3 asks “how cancer is affecting your family’s everyday life.” One participant was not sure if the question referred to *her* cancer.

Recommendation: We recommend changing these questions to refer to “your cancer.”

Several participants had difficulty with Q6, which asks about discussions about “what is important to your family or caregivers when planning your cancer care.” Two participants interpreted the question as asking about what is important to family and family preferences, not addressing whether they discussed this with the doctor (in part, this is an issue of ignoring the question stem). Another participant said he would answer differently about family and caregivers.

Recommendation: We recommend dropping Q6.

Two participants had difficulty with Q7 which asks about discussion of “your ideas and preferences” when planning care. One participant said he does not have any ideas, but “just does what the doctor tells him.” Another thought the question should ask about preferences only.

Recommendation: We recommend changing to “your preferences” (drop “ideas”).

Several participants said Q8 (“To what extent does your doctor... let you know when it’s time to change your cancer care plan?”) was not relevant to them. One participant thought “let you know” sounded condescending.

Recommendation: We recommend dropping Q8.

Q12 and Q13 both ask about discussion with doctor about any problems following the cancer care plan. Q12 was better understood.

Recommendation: We recommend dropping Q13 and revising Q12 to use “plans for your cancer care.”

Participants had difficulty following Q14 (to what extent does your doctor discuss how your family or caregiver can make it easier for you to follow your cancer care plan?). They were unsure who the discussion was with (doctor and patient or doctor and family?).

Recommendation: We recommend dropping Q14.

Questions 15 through 20 ask about coordination of care, including whether the doctor explain next steps.

Q16 and Q17 ask about coordination with other health care providers. These are very repetitive with several crosscutting and fostering healing relationships questions (see Crosscutting).

Recommendation: See the recommendation about consolidating these questions (Crosscutting).

Q20 asks “To what extent does your doctor... discuss how your culture might affect how your cancer care is delivered.” As discussed previously (see Questions Dealing With Culture and Background), multiple respondents said that culture was not relevant to their cancer care.

Recommendation: We recommend further testing of questions related to culture and background (as discussed in Questions Dealing With Culture and Background).

Questions 21 through 22 ask about assistance from doctor in identifying resources for self-management.

Q22 asks about doctor’s assistance in findings resources (e.g., help with transportation, cost of medicine). One participant said these examples do not apply because he is insured.

Recommendation: We recommend dropping Q22 because it is too heavily focused on financial/insurance-related issues. Other types of assistance are addressed in other questions.

Questions 23 through 32 ask about discussions with the doctor about managing their own health.

Q24 and Q30 are very similar; Q24 asks *to what extent* they discuss “changes you can make to take better care of your health (such as diet, exercise, dealing with stress.” Q30 asks *how often* they discuss “ways to manage you own health (such as diet, exercise, dealing with stress).” Q31 is redundant with Q30 (how often discuss “ideas for managing your own health”). Several participants preferred Q30.

Recommendation: We recommend dropping Q24 and Q31.

Crosscutting

The crosscutting questions ask about how the doctor communicates (e.g., listening, showing respect) and about roles and responsibilities. These questions worked well overall, and we identified only the following issues:

Questions 13 and 14 ask about how the doctor seems to coordinate and communicate with other health care providers.

Q14 asks to what extent the doctor “seems to work with other health care providers involved in your cancer care.” Two participants thought this question was redundant with Q13, which asks to what extent the doctor “seems to communicate with other healthcare providers so that they are up-to-date with test results and the cancer care you receive.” As noted in Fostering Healing Relationships and Enabling Self-Management, very similar questions were also tested as part of the fostering healing relationships (Q33 and Q34) and self-management (Q16 and Q17) functions; these questions should be considered

together with the cross-cutting questions.

Recommendation: All of the questions performed well, but they are highly overlapping. We recommend dropping Q13 because it is narrower than Q14. We also recommend considering dropping fostering healing relationships Q33 and enabling self-management Q16 and Q17.

Background

Participants answered a set of background questions to provide context for their responses to the PCC questions. These questions ask about their cancer diagnosis and treatment and about their main doctor. Testing these questions was not part of the scope of work and thus was not our primary focus. However, we did identify several issues of interest:

Questions 1 through 4 ask about their cancer diagnosis and treatment.

Q2 asks what type(s) of cancer they have been diagnosed with and some participants had types not listed (head/neck, ovarian, cervical).

Recommendation: We recommend adding more cancer types (based on prevalence).

Q3 asks about treatment status. Participants who had surgery were confused about how to answer because they did not consider surgery to be “treatment.”

Recommendation: We recommend adding an introduction stating that there are different types of cancer treatment, including surgery.

Q4 asks what type(s) of treatment they have received. Some participants were confused (or, in one case, insulted) because the instructions say not to consider a biopsy as treatment: “It hurt and I have the scar to provide it” or “they still cut you.” Some participants were unfamiliar with some of the treatment types (complementary or alternative medicine; targeted, biologic, and immune therapies).

Recommendation: We recommend revising the surgery response option to read “do not include biopsy or insertion of medication ports” (rather than “do not consider biopsy or insertion of medication ports to be surgery”).

Questions 8 through 11 ask about their main doctor and frequency of visits.

Most participants could identify their main doctor’s specialty area (Q8); one was unsure of the difference between a medical oncologist and a radiation oncologist; others suggested additional specialists to include.

Recommendation: We recommend adding gynecologist/gynecological oncologist, surgical oncologist.

Some participants had difficulty answering Q11 about how many times they saw their main doctor in the last 12 months. Several were unsure whether and how to count contact with their doctor while hospitalized. Also, two participants calculated their answer in terms of number of visits per month (e.g., 2 times/month), and one had difficulty converting that to the response options.

Recommendation: We recommend considering adding instructions to count both inpatient and outpatient visits with the doctor and how to count inpatient visits. We also recommend revising response options to include a higher number of visits (up to 20 or more visits).

Next Steps

Overall, the cognitive testing findings suggest that the PCC questions functioned well. The cancer patients who participated in the testing were generally able to understand the questions, apply them to their own experiences, and use the response scales to choose an appropriate answer. Furthermore, many participants reflected that the questions measured important aspects of their interactions with cancer care providers and, in some cases, made them realize how their care could have been improved. One patient commented, *“The questions are amazing because you realize what you didn’t get.”*

We identified issues with specific questions (e.g., issues related to wording, structure, perceived redundancy, and personal relevance) and also several general issues that should be addressed. Based on these findings, the next step is to revise specific questions, drop other questions, and make other revisions (e.g., to introductory text) as appropriate. In doing so, we recommend paying attention to the considerations discussed in the sections that follow.

Formatting the Survey

We developed a survey format for the cognitive interviews in which questions were grouped into blocks of items that dealt with related concepts (e.g., blocks of questions about openness/honesty or attention to emotions). We recommend retaining this approach for the final survey because it aids respondent comprehension. The format presents a common stem with a series of individual items listed under each stem, and all items in the block use a common response scale. It helps to reduce the reading requirements and burden on respondents of having to read the same stem repeatedly. Another advantage of this approach is that researchers can insert one or more blocks of items as relevant in survey instruments.

However, we also recommended some formatting changes to draw respondents’ attention to question stems, specifically using bold text. In addition, for some items key words from the stem (e.g., “discuss”) may be moved to the body of the question (see Question Stems).

Addressing Redundancy Across Survey Items

By design, we tested different versions of some questions, resulting in the appearance in some redundant or overlapping items. Although redundancy in items is anticipated at the item development stage, redundancy in actual surveys can frustrate respondents, resulting in both item and unit nonresponse. We provide recommendations about questions to drop or to consider dropping based on the cognitive testing findings. However, we recommend retaining some level of redundancy for the next stage of field testing. Ideally, final decisions about culling items would be made based on field testing results.

Conducting Additional Formative Research and Cognitive Testing

The cognitive interviews point to the need for additional formative research in a few areas. In particular, additional formative research is needed to gain a better understanding of how patients view uncertainty in the context of their cancer care (e.g., whether they perceive different categories of uncertainty that could frame the questions) and determine the best approach to revising the managing uncertainty questions. We suggested several alternative strategies for handling this PCC function in the final survey (see Managing Uncertainty). Because significant revisions are required, an additional round of cognitive testing will be needed to understand how the questions perform. For the making decisions questions, additional cognitive testing would

also be useful to assess whether a revised introduction is effective in directing respondents to think about the full range of decisions involved in cancer care, not just the “big” decisions (see Making Decisions). Finally, we recommend additional cognitive testing to test questions about background and culture, specifically to assess whether patients perceive these questions as personally relevant and important. For these items, cognitive testing with minority patients will be particularly important (see Questions Dealing With Culture and Background).

Planning for Field Testing

Although cognitive interviews are valuable in identifying possible problems with survey items, because of the qualitative nature of the data collected, they do not indicate how well questions will work on the final version of the survey. Thus, we recommend field testing the revised items with diverse groups from different care settings. Data from large-scale field testing can then be subjected to psychometric analyses to assess how well individual questions and scales function to measure PCC in cancer care. Based on these data, additional modifications can be made such as dropping unreliable or poorly functioning items, combining scales, and implementing other measures that may be necessary. In addition to evaluating the psychometric properties of the items, field testing should also examine possible differences in demographic characteristics that may affect how participants respond. For instance, the type of cancer and phase of cancer care may have a significant impact on the way patients respond to questions—particularly with regard to discussions about treatment options and other decisions, family involvement, and dealing with uncertainty. Furthermore, field testing can address whether gender and other demographic characteristics, cancer care setting, and other factors influence responses.

Draft PCC Survey Items

The draft PCC items are included in Appendix V. The items reflect the findings from the cognitive testing. Further cognitive testing and field testing with diverse patient populations are needed to finalize a set of PCC patient survey items.

Objective 4: Considerations for Developing a Physician Survey To Assess PCC^e

Background

In 2007, RTI International began work on Advancing Measurement of Patient-Centered Communication in Cancer Care, a project sponsored by the National Cancer Institute (NCI) and the Agency for Healthcare Research and Quality (AHRQ). As part of an initiative on patient-centered communication (PCC), NCI developed a conceptual model (Figure 1) that defines six functions of PCC: fostering healing relationships, exchanging information, making decisions, enabling patient self-management, managing uncertainty, and recognizing and responding to emotions.¹

In Phase 1 of the project, we developed a comprehensive inventory of measurement domains and subdomains, aligned with the PCC functions as presented in the conceptual model, by reviewing relevant literature, consulting experts, and conducting a small qualitative study involving patient interviews.⁹ In Phase 2 of the project, we developed and tested PCC items for a patient survey. The measurement development process involved multiple steps, including inventorying existing survey and other measurement instruments, identifying candidate items that could be used or adapted for a patient survey, identifying gaps in the existing item pool and developing new items, and testing items with cancer patients using a cognitive interviewing approach.^{10,11}

Overall, the project focused on the development of survey questions for patients. However, assessment from the physician perspective also is essential for a comprehensive understanding of PCC in cancer care. This report provides guidance and discusses the future development of questions for a physician survey. More specifically, it discusses the goals and framework for a physician survey, the rationale for focusing initially on physicians (vs. other health care professionals), the frame of reference, and the roadmap for instrument development.

Goals and Framework for the Physician Survey

The goals and framework for a physician survey parallel those for the patient survey, including the following:

- **Survey purposes.** The survey could be used for a number of purposes, including quality assessment, population surveillance, intervention research, and training evaluation. For quality assessment or other purposes, a physician survey could be used in conjunction with a patient survey to obtain a comprehensive assessment of PCC from both the patient and physician perspectives.
- **PCC conceptual model as framework.** The survey would be based on the NCI conceptual model of PCC and survey questions would assess the six PCC functions. Overall, we anticipate that the measurement domains and subdomains as developed for the patient survey would also apply to the physician survey, although potentially there could be modifications. We anticipate that many of the questions developed for the patient survey could be adapted to assess PCC from the physician perspective (see attached sample PCC items).

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- **Applicable for different health care settings.** Survey items should be applicable for physicians with different specialties who provide cancer care in a range of healthcare settings from small private practices to multispecialty practices, community cancer centers, and academic cancer centers. As discussed below, a physician survey also could be adapted for other health care professionals (see Focus on Physicians Versus Other Health Care Professionals).

Considerations in Developing a Physician Survey

Focus on Physicians Versus Other Health Care Professionals

Cancer care is provided by a range of health care professionals, including different physician specialties—such as medical oncologists, radiation oncologists, surgeons, obstetricians/ gynecologists, and urologists—as well as primary care physicians. Our research with cancer patients found that patients identify different types of physicians as their “main doctor,” depending on their type of cancer, type(s) of treatment, and other factors. In some cases, who patients consider to be their main doctor may change over the course of care (e.g., from surgeon to medical oncologist).¹¹ Other clinicians and healthcare professionals also play key roles in cancer care, including nurse practitioners, physician assistants, clinical nurses, infusion nurses, floor nurses on oncology wards, dietitians, physical therapists, patient navigators, chaplains, and social workers. As a first step, we recommend developing a survey targeting physicians. Items could then be adapted for other healthcare professionals, such as nurse practitioners, physician assistants and advanced clinical nurses, and also potentially for other members of the cancer care team.

Another important consideration in developing a physician survey is that, depending on the physician’s specialty, he or she may see cancer patients exclusively or a mix of cancer and non-cancer patients. For example, a solid tumor oncologist may only see cancer patients, whereas a gastroenterologist may only see a few cancer patients in his or her practice. It will be important to introduce and frame questions so that respondents consider cancer patients only in their responses. Also, in the formative research and cognitive testing of survey questions, it will be important to explore whether and how physicians are able to focus on cancer patients specifically in selecting their answers.

Roles and Responsibilities of the Cancer Care Team

Physicians and other members of the cancer care team can play different roles in communicating with patients and family members. In some instances, physicians may consider it their role to “do it all”—that is, play the lead role for all aspects of PCC. In other situations, physicians may be part of a larger team and may rely on nurses, patient navigators, or other members of the care team for some aspects of communication with patients and family members. Our research with patients found that nurses frequently play a major role in PCC, particularly in terms of emotional support and enabling patient self-management.¹²

We recommend that the physician survey (and ultimately surveys for other health care professionals) assess *all* aspects of PCC. Ideally, physicians should be capable and comfortable with each of the PCC functions, even when they work as part of larger care teams in which other healthcare professionals also play key roles in PCC. It will be helpful to include questions to understand the context within which the physician provides treatment as well as the composition of the care team. For example, questions could ask what types of healthcare professionals

comprise the cancer care team and who plays the different roles in communication with patients and family members.

Ultimately, comprehensive PCC assessment would ideally examine PCC across *all* members of the cancer care team, as well as from the patient perspective. However, as noted above, we recommend developing a survey for physicians as a first step.

Frame of Reference

When asking physicians about PCC, it is important to consider the frame of reference for these questions because it will define the focus of the questions, the time frame, and the way in which respondents are to answer questions. For example, questions could ask physicians about their most recent patient encounter, patient encounters over a period of time, or more broadly what they tend to do in general (i.e., communication behaviors in typical encounters). There are two major framing issues to consider for the physicians survey: the time frame and specificity of information requested.

Timeframe

Specifying the time frame is critical so that all respondents refer to a similar period of time in responding to the questions. Many of the surveys about communication behaviors focus on a relatively recent time frame, such as the last encounter, previous 24 hours, or the past week (e.g., Roberts, Cox, Reintgen, et al., 1994;¹³ Siminoff, Graham, and Gordon, 2006;¹⁴ Street, Voigt, Geyer, et al., 1995;¹⁵ Takayama, Yamazaki, and Katsumata, 2001¹⁶).

There are tradeoffs to consider with using different time frames for PCC survey questions. If questions ask about recent experiences (e.g., last patient encounter), responses may not be typical of the physician's communication behavior in general. However, if questions ask about longer periods of time, there may be issues of recall bias, where the physician may indicate that he or she has engaged in a particular behavior or addressed an issue in communication that is either outside the time frame or simply did not occur.^{17,18}

Specificity of Information Requested

The second major framing consideration is the specificity of the information being requested. Questions may be framed in terms of specific events or patients (e.g., most recent patient encounter, specific type of patient) or can be asked in general terms. As with the consideration of time frame, the more specific the question is, the more accurate the response tends to be—but it may be less representative of how the clinician typically communicates in patient encounters. Also, respondents may perceive more specific questions as difficult to answer because they require more effort to recall. Consequently, some surveys ask how the respondent *typically* handles a particular type of communication, with the understanding that the response may not be accurate for each specific patient encounter.

Framing Questions for the Physician Survey

When thinking about how to frame the questions for the physician survey, both time frame and specificity should be considered to ensure that the desired information is collected in a way that is easy for respondents. Framing considerations is particularly important given that physicians, depending on their care setting, may have a high volume of patients. Consequently, physicians may be most likely to report their typical communication behavior with patients overall, unless specifically directed to do otherwise.

Considering the tradeoffs of time frame and specificity, it may be best to ask questions about a physician's perceptions about how often, what percentage of time, or with what proportion of patients they carry out different communication behaviors. Responses can be Likert-type scales focused on frequency (e.g., all of the time, most of the time, etc.), the percentage of time when seeing patients (e.g., 90–100%, 80–90%, etc.), or the proportion of patients (e.g., all patients, most patients, etc.). (See attached sample questions illustrating these different response options.) It will be important to test response scales with physicians to assess how they interpret and use them.

Ceiling Effects

Another important consideration in developing the physician survey is how to avoid or minimize potential ceiling effects that would occur if physicians tend to rate their own communication behaviors highly. Ceiling effects are frequently encountered in satisfaction surveys in healthcare and consumer research, where the survey findings often result in all healthcare professionals being very highly rated regardless of actual patient experience.^{19,20} Ceiling (and floor) effects are potential major problems in measurement, as survey responses show very little variance and therefore make it difficult to demonstrate differences among respondents as well as change over time (e.g., pre- and post-intervention).²¹

The most common method of addressing ceiling effects is to use response scales and question framing to encourage a greater variety of responses. For example, introductions and examples provided in the survey can encourage respondents to use more of the response scale than they would otherwise. In the patient version of the PCC survey, the introductions stated that not all physicians do everything related to communication well and that the purpose of the survey is to obtain patients' honest assessment of their experience. This type of framing gives respondents permission to provide negative ratings, which can help to minimize ceiling effects.

In addition to framing, it is also common for question writers to consider whether the response scale provides enough variability to accurately map onto the attitudes, perceptions, and behaviors of the respondents. For the physician survey, it will be important to offer response scales that make sense to the respondents and provide them a wide enough range that they do not feel that only the upper (ceiling effect) or lower (floor effect) ends of the scale fit their answers well. In cognitive testing, it will be important to assess how respondents use the response scales; specifically, whether they use the full range of responses.

Respondent Burden

Survey length and respondent burden are important considerations for the physician survey. These factors, as well as mode of administration, can influence response rates and also data quality.²² Physicians have demanding work schedules; are frequently contacted by researchers, pharmaceutical companies, and others; and are hard to reach directly because of gatekeepers, such as receptionists, clinical nurses, and other members of the medical team. Consequently, response rates among physicians average about 10% lower than studies with the general population.²³ Consequently, the final physician survey must balance the need for comprehensive PCC assessment with consideration for respondent burden.

Experience from the implementation of other health care professional surveys can inform decisions about the number of items and other factors that influence response rate (e.g., mode of data collection, survey format).²² To minimize the survey length, we recommend reviewing the PCC domains and subdomains for each function and identifying those that may be of lower

priority for the physician survey. Stakeholders can provide important input on priorities for PCC measurement (see Roadmap for Measurement Development).

Repeated Administration Effects

The process of completing the survey may raise physicians' awareness of PCC and prompt them to self-assess and reflect on their interactions with patients. Specifically, respondents may reflect on their own strengths and weaknesses relative to the PCC "gold standard," as represented in the survey items. This phenomenon occurred with the patient survey. For example, some patients who participated in the cognitive testing commented that the experience made them realize what was missing in their own interactions with clinicians and what should ideally occur in PCC.¹⁰

As a result of completing the survey, physicians may recognize areas for improvement and make changes in their PCC behaviors. Consequently, the process of completing the survey could act as an intervention, influencing physicians' PCC knowledge, awareness, and behaviors. It will be important to take these repeated administration effects into account in research design and data analysis.

Roadmap for Measurement Development

Given the variety of challenging issues that will affect PCC measurement from the perspective of physicians and other clinicians, we recommend building on the work completed to develop patient measures (e.g., as noted above, relying on the same PCC model and domain and subdomain structure) and using a similar development process. Ideally, this process would include the following elements:

- **Expert advisory group.** As in the patient survey project, we recommend establishing an expert advisory group, involving many of the current experts for the purpose of continuity with the current project and also possibly new members who offer expertise in such areas as physician communication skills training and evaluation.
- **Stakeholder input.** This step would involve seeking input from organizations—such as healthcare systems, insurers, medical schools, certification organizations, and education and training organizations—that could potentially use the results of the physician PCC survey for quality assessment, training evaluation, or other purposes. These potential survey users could provide valuable input on priorities for measurement, mode of administration, and considerations for survey administration with different types of physicians and in different care settings. Various approaches could be used to obtain stakeholder input, including interviews, meetings, and/or written input.
- **Formative research.** This part of the work will focus on reviewing the current PCC framework and determining any adjustments needed to the measurement domains and subdomains (i.e., additions, deletions, revisions) for the purpose of the physician survey. This research could involve focus groups or qualitative interviews with physicians in different specialties and working in a variety of care settings to gain an in-depth understanding of the physician's PCC experience and perspective.
- **Review existing literature and instruments.** This step follows the same basic process as that used to develop the patient PCC measures. The research team would review the literature on physician measures relevant to PCC and identify candidate measures that have been published or used in research. An inventory of items from this literature would be constructed that matches survey questions, observational protocols, and other forms of

measurement with the PCC framework. The items would then be culled down to a list of nonredundant items that cover all of the relevant domains of the PCC framework. We included a number of physician observation and survey measures in the patient instrument and item inventory process (e.g., Patient-Practitioner Orientation Scale, Roter Method of Interaction Process Analysis observational scales, Cancer Consultation Preparation Package, Facilitation of Patient Involvement Scale, and the Patient-Centered Behavior Coding instrument) that could be used as a starting point for the inventory.

- **Item writing, revision, and review.** Once a pool of items has been identified from existing instruments, they can be adapted or revised as needed to align with the PCC functions. In areas where there are no items to address important PCC concepts, the research team would develop new items. The final set of candidate items would then be systematically reviewed both by subject matter experts in PCC (i.e., the expert or advisory panel) and by survey methodologists who can evaluate whether questions conform to best practices in writing survey items.
- **Cognitive testing.** After a draft set of items has been developed and reviewed, the cognitive testing should be conducted with physicians. Cognitive testing participants would include physicians with different specialties who are working in different care settings. Cognitive testing would be designed to assess survey items for comprehension, consistent interpretation across patients, ability to recall necessary information, appropriateness, and lack of overlap.⁵ During the cognitive interviews, the interviewer would provide respondents with the survey and ask them to “think aloud” as they complete it, explaining how they recall information and arrive at their answer choice.⁷ As with the cognitive testing conducted with patients, we expect that cognitive testing with physicians will identify issues that will likely require revision, addition, or deletion of items from the draft set of items.
- **Field and psychometric testing.** Although cognitive testing is valuable in identifying possible problems with survey items, because it is a qualitative technique it does not indicate how well questions will work in the context of a final survey. To address this issue, we recommend field testing the revised items with a diverse sample of physicians with different specialties and from different care settings. Data from large-scale field testing can then be subjected to psychometric analyses to assess how well individual questions and scales function to measure PCC in cancer care from the physician perspective. Based on the results, additional modifications can be made, such as dropping unreliable or poorly functioning items or revising scales. In addition to evaluating the psychometric properties of the items, field testing also can be used to examine possible differences by physician characteristics, cancer care setting, and other factors.

Ideally, the development of physician measures would follow the process outlined above to ensure that measures address all of the important elements of PCC, frame questions in terms that are easy to understand and are relevant to physicians, and provide high-quality data on PCC in cancer care from the perspective of physicians. However, some steps could potentially be streamlined, if time and/or cost constraints are present. For example, the effort required for review of existing literature and instruments could be minimized by building on the resources identified in the patient survey project. We strongly recommend conducting cognitive testing and field testing to ensure the development of high-quality measures.

Considerations for Next Steps in PCC Measurement Development

The Advancing Measurement of Patient-Centered Communication in Cancer Care project lays the groundwork for the assessment of patient-centered communication (PCC) in cancer care. We used a systematic approach to develop PCC items for a patient survey, beginning by inventorying existing survey and other measurement instruments and items. Subsequently, we developed and tested a total of 220 items, and ultimately finalized a set of 147 candidate PCC items. Additional steps are needed to finalize a PCC patient survey.

As detailed in Objective 3, Cognitive Testing of PCC Items, the recommended next steps are as follows:

- **Conduct additional formative research** to inform the managing uncertainty items. In the Cognitive Testing report, we detail the challenges identified with the managing uncertainty items and recommend different approaches to structuring these items. One approach, for example, would be to map the items to different categories of uncertainty that are meaningful to patients.
- **Conduct additional cognitive testing**, especially for the managing uncertainty items, as these will need to be revised substantially. Cognitive testing should involve patients from different racial/ethnic minority groups, patients with lower formal education levels, and patients receiving care in diverse cancer care settings.
- **Conduct large-scale field-testing** of the patient survey with diverse cancer patients and in a variety of cancer care settings. Field testing with patients from different racial/ethnic groups and patients with lower educational levels is particularly important. Large-scale field testing will allow researchers to conduct psychometric assessments of the items and scales.
- **Finalize the patient survey** based on the findings from large-scale field testing. It may be desirable to develop short and long forms of the survey for different uses, such as for intervention research, quality assessment, and population surveillance. It may also be desirable to develop modules for different phases of care or clinical contexts (see below).

By design, we developed PCC survey questions that refer to patients' communication experiences *generally* rather than referencing specific phases of care or clinical contexts. Among the project team and experts, considerable discussion focused on the best approach in terms of the appropriate level of generality versus specificity for the survey questions. Ultimately, we decided to develop more generic questions, with the idea that many of the questions could be adapted as needed to refer to specific aspects of care. For example, questions can be reframed to reference specific points in care by adding such language as "Thinking about when you first learned about your cancer diagnosis..." or "Thinking about when you and your doctor were making plans for your treatment..." Additional context-specific questions or modules also could be incorporated into a PCC survey at a later point.

The findings from the first round of cognitive testing suggest that greater specificity would be helpful for some of the survey items. For instance, respondents said they would answer particular questions quite differently for different phases or aspects of their care. Also, some respondents thought that certain questions were not relevant to their cancer care situation. We found this most often for the questions about making decisions and managing uncertainty; some respondents said they had not experienced any uncertainties or faced any decisions, so they were

unsure how to answer these questions. Filtering questions would be helpful so that patients who have not experienced a particular situation are not asked questions relevant to that situation. For example, patients that have not experienced a transition in treatment goals would not answer questions related to communication about that change.

Further work is needed to determine the phases of care that are meaningful from the patient perspective, so that questions or modules can be developed that reference these phases. The standard phases of care, as defined by the National Cancer Institute, include prevention/screening, diagnosis, treatment, post-treatment/survivorship, and end of life. However, these phases of care may not be intuitive or meaningful from the patient perspective. Consequently, the project team and experts tentatively identified the following periods of the cancer care experience as meaningful for the patient: awareness that something is wrong (screening and diagnosis process); receiving bad news, further diagnostic testing, treatment discussion and planning; beginning of treatment, period of active treatment, evaluation of treatment effectiveness, and decision making; and transition in care (see Objective 1, Refine Measurement Model). Another approach would be for some of the questions to reference specific and discrete communication tasks or milestones that experts can agree should occur in cancer care. These might include communication about the diagnosis and prognosis, treatment planning, coordination of care, and transitions in treatment goals.

Additional work also is needed to develop a normative framework or “gold standard” for the types of communication that should occur in cancer care overall and also at specific points in care. We can assume that the relative importance of the different PCC functions and of specific domains and subdomains within each function varies at different points in cancer care. However, empirical data are needed to understand the patient and clinician perspectives about the relative importance of different PCC functions over the course of care. Moreover, research is needed to understand how PCC, and specific PCC functions, affect both shorter term and longer term patient outcomes. Future research in different cancer care settings can explore how systems level factors facilitate or hinder achieving these “gold standard” communication behaviors.

A subsequent phase of large-scale field testing will provide important data to help guide the further development and refinement of the PCC measures.

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Appendix A. Objective 1: Agenda for the Expert Advisor Meeting

Advancing Measurement of Patient-Centered Communication in Cancer Care

December 17, 2009

John M. Eisenberg Building
Agency for Healthcare Research and Quality (AHRQ) Conference Center
Watts Branch Conference Room
540 Gaither Road
Rockville, Maryland 20850

Teleconference: 1-866-642-0777

Participant Code: 9155071

8:00 a.m.	Transportation from hotel to AHRQ (shuttle to leave hotel at 8:00)
8:30-9:00 a.m.	Continental breakfast
9:00-9:30 a.m.	Welcome and Introductions <i>Neeraj Arora, PhD (NCI) and Bill Lawrence, MD, MS (AHRQ)</i> Review Agenda, Meeting Objectives, Assumptions, Discussion Questions and PCC Functions <i>Lauren McCormack, PhD, MSPH (RTI)</i>
9:30-10:45 a.m.	Present and Discuss Options for PCC Conceptual Model <i>Rick Street, PhD, Neeraj Arora (NCI), Ron Epstein, MD, Pam Williams-Piehot, PhD (RTI), and Tony Back, MD</i>
10:45-11:00 a.m.	Break
11:00 a.m.–12:00 p.m.	Discuss Clinical Contexts and other Considerations for Focusing Measurement <i>Katherine Treiman, PhD (RTI) and Eric Nadler, MD</i>
12:00-1:00 p.m.	Lunch (catered)
1:00-2:15 p.m.	Discuss Fundamental Measurement Issues and Challenges <i>RTI and Group Discussion</i>
2:15-3:15 p.m.	Finalize the PCC Conceptual Model <i>RTI and Group Discussion</i>
3:15 -3:30 p.m.	Next Steps for Measurement: Where Do We Go from Here? <i>Lauren McCormack (RTI), Neeraj Arora (NCI) and Bill Lawrence (AHRQ)</i>

Appendix B. Objective 1: Slides From the Expert Advisor Meeting

Slide 1



turning knowledge into practice

Advancing Research Methodology for Measuring and Monitoring Patient-Centered Communication in Cancer Care Expert Advisor Meeting

March 5, 2009

www.rti.org

February 27, 2009

Slide 2

Project Officers

- Neeraj Arora, PhD, NCI
- William Lawrence, MD, MS, AHRQ

Slide 3

RTI and Other Project Staff

RTI

- Lauren McCormack, PhD, MSPH, Project Director
- Katherine Treiman, PhD, Associate Project Director
- Douglas Rupert, MPH
- Pamela Williams-Piehot, PhD
- Eric Nadler, MD, MPH, Baylor Health Care System
- Richard Street, PhD, Texas A&M

Slide 4

Meeting Participants

- Scientific Evaluation Group
- Expert Advisors
- Additional NCI and AHRQ Staff

Slide 5

Meeting Objectives

- Confirm patient-centered communication (PCC) functions and measurement domains
- Discuss priority areas for measurement
- Obtain input for next steps in measurement development

Slide 6

Project Update

- SEG meeting in 2008
- Selected 2 experts for each function
- Met multiple times via phone to develop domains/subdomains
- Conducted second round of primary data collection with cancer patients/families
 - Circulated for review and revision
 - Considered additional theory, literature
 - Added sample items

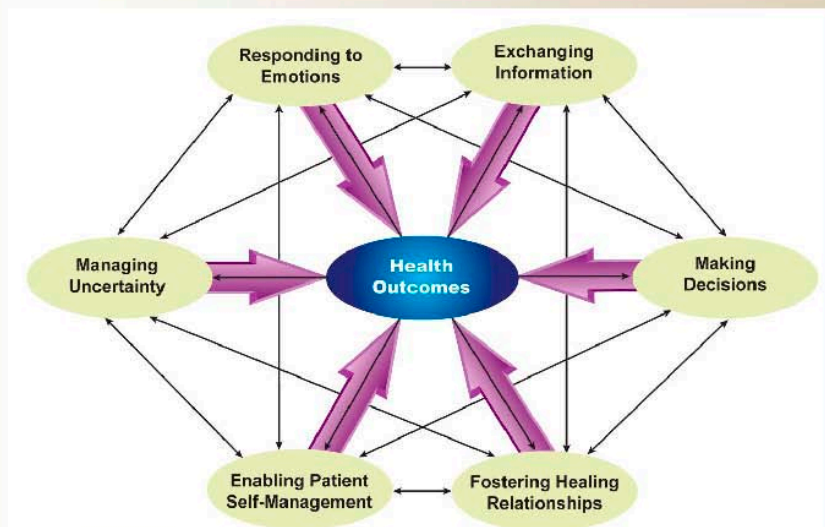
Slide 7

Patient-Centered Communication

- Eliciting, understanding, and validating the patient's perspective
- Understanding patient within his/her own psychological and social context
- Reaching shared understanding of the problem and its treatment
- Empowering patient through meaningful involvement in choices related to his/her health

Slide 8

Core Functions of Patient-Centered Communication



Epstein RM, Street RL, Jr. Patient Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007.

Slide 9

Patient-Centered Communication Measurement Development Activities

- Conceptualize
- **Consensus development**
- Item development
- Item testing
- Item pool
- Pilot studies/intervention research
- Reduced set of items
- Wide-scale implementation

Slide 10

Properties of Measures

Predictive: predictive of outcomes

Parsimonious: limited and simple

Reliable: perform in a consistent manner

Robust: can be used in different settings, populations, stages of cancer care continuum

Practical: can be implemented nationally as part of the evolving health information infrastructure

Theoretically based: build on existing frameworks, theories, and literature

Slide 11

How Patient-Centered Communication Measures Can be Used

1. Population-based surveillance
2. Quality assessment and monitoring
3. Research and intervention studies

Slide 12

Agenda

- How PCC fits with AHRQ's research agenda
- Update on PCC from NCI
- Review each PCC function
 - 3 in the morning
 - 3 in the afternoon
- Wrap-up
- Next steps

Slide 13

Information Exchange

- What is the best way to handle overlap with other function?
- Do domains and subdomains work across different settings, providers, stages in cancer care continuum, and communication modality?
- Which domains and subdomains are priorities for purposes of population surveillance? Quality assessment and monitoring?
- Are some domains/subdomains less suitable for patient self-report? What are other methodological considerations?

Slide 14

Fostering Healing Relationships

- What is the best way to handle overlap with other functions?
- Do partnership-building communication behaviors (e.g., active listening, not interrupting) fit best in this function?
- Do domains and subdomains work across different settings, providers, stages in cancer care continuum, and communication modality?
- Which domains and subdomains are priorities for purposes of population surveillance? Quality assessment and monitoring?
- Are some domains/subdomains less suitable for patient self-report? What are other methodological considerations?

Slide 15

Recognizing and Responding to Emotions

- What is the best way to handle overlap with other function?
- Do domains adequately capture whether providers help with emotional adjustment?
- Do domains and subdomains work across different settings, providers, stages in cancer care continuum, and communication modality?
- Which domains and subdomains are priorities for purposes of population surveillance? Quality assessment and monitoring?
- Are some domains/subdomains less suitable for patient self-report? What are other methodological considerations?

Slide 16

Managing Uncertainty

- What is the best way to handle overlap with other functions?
- Do domains and subdomains work across different settings, providers, stages in cancer care continuum, and communication modality?
- Which domains and subdomains are priorities for purposes of population surveillance? Quality assessment and monitoring?
- Are some domains/subdomains less suitable for patient self-report? What are other methodological considerations are there?
- How can we assess uncertainties outside the patient–provider relationship that can be detrimental to the relationship?

Slide 17

Making Decisions

- What is the best way to handle overlap with other functions?
- How should implementing the decision be reflected since it occurs outside the clinical setting?
- Do domains/subdomains capture two-way communication?
- Do domains and subdomains work across different settings, providers, stages in cancer care continuum, and communication modality?
- Which domains and subdomains are priorities for population surveillance? Quality assessment and monitoring?
- Are some domains/subdomains less suitable for patient self-report? What are other methodological considerations?

Slide 18

Enabling Self-Management and Patient Navigation

- Does organizing framework (5 A's and 5 R's) work?
- Do domains/subdomains reflect “should do,” “how to,” and “can do” communication?
- Do domains/subdomains reflect that self-management occurs outside the clinical setting?

Slide 19

Enabling Self-Management and Patient Navigation (cont.)

- Is separating Patient Navigation into its own function warranted?
- Do domains/subdomains reflect role of patient navigators?
- Do domains and subdomains work across different settings, providers, stages in cancer care continuum, and communication modality?
- Which domains/subdomains are priorities for population surveillance? Quality assessment and monitoring?
- Are some domains/subdomains less suitable for patient self-report? What are other methodological considerations?

Slide 20

Wrap-Up of Functions

- Are functions equally important to measure or does some take higher priority?
- How to incorporate cross-cutting domains?
 - Communication related to time and setting
 - Perceptions about roles of different members of cancer care team related to each function
 - Partnership-building communication behaviors
- Measurement challenges:
 - Limitations of patient self-report
 - Measuring experiences over time
 - Measuring experiences with multiple providers

Slide 21

Next Steps

- Conceptualize
- Consensus
- Item development
- Item testing
- Item pool
- Pilot studies/intervention research
- Psychometric analysis, short form development
- Wide-scale dissemination/implementation

Slide 22

How Do We Get from Here to There?

- **Who**—Which populations for item testing, pilot studies?
- **What**—What kinds of testing, pilot studies?
- **Where**—Which settings for item testing, pilot studies?
- **When**—Time frame?

Appendix C. Objective 1: Notes From the Expert Advisor Meeting

Meeting Attendees

<i>AHRQ</i> Bill Lawrence Darren Mays	<i>RTI:</i> Lauren McCormack Katherine Treiman Pam Williams-Piehot Murrey Olmsted [via telephone]
<i>National Cancer Institute:</i> Neeraj Arora Steve Clauser Lila Finney-Rutten Paul Han Brad Hesse	<i>Project consultants</i> Eric Nadler Richard Street
<i>Expert Advisers and Scientific Evaluation Group (SEG)</i> Ron Epstein Tony Back Kathy Mazor Bryce Reeve	<i>Other participants:</i> Kristen Carman, AIR

Meeting Background and Objectives

The goal of this project, sponsored by the National Cancer Institute (NCI) and the Agency for Health Care Research and Quality (AHRQ), is to develop approaches for assessing patient-centered communication (PCC) in the context of cancer care. In Phase I, the project team identified measurement domains and subdomains for the PCC functions as defined in the NCI conceptual model: (1) exchanging information, (2) fostering healing relationship, (3) recognizing and responding to emotions, (4) managing uncertainty, (5) making decisions, and (6) enabling patient self-management and navigation. The goal of Phase II is to refine the PCC conceptual model; identify, develop, and test PCC measures; and create surveys for patients and providers.

The surveys will be designed for use in organizational-level quality assessment and for population-level surveillance.

This meeting convened the project's Scientific Evaluation Group (SEG) and Expert Advisers to provide input for the Phase II activities. The primary objectives of the meeting were to:

- Review and refine the patient-centered communication (PCC) conceptual model;
- Determine the clinical contexts for focusing PCC measurement; and
- Address measurement issues and challenges associated with measurement of PCC.

1. Meeting Summary

PCC Conceptual Model

We reviewed the original PCC model included in the NCI monograph and several potential modifications.

Key Discussion Points

- Approach to the original model (in NCI monograph) was functional; functions extend beyond behavior and capture the interactive process. The six functions are distinct but closely related.
- One alternative model depicts functions embedded within one another. With this model, would have 6 subscales and individual items capturing embedded functions.
- Relationship suffuses the functions more than reflected in original model. We would expect to see that if the relationship is rated poorly (e.g., no respect), then the other functions won't make sense.
- Concepts of "sense making" and collaborative cognition need to be incorporated into the model.
- Some of the terminology suggests a clinician-centered view rather than a patient-centered view (e.g. "emotion-focused management strategies"). Some elements of the functions seem to go beyond PCC (e.g., assessment for depression).
- Relevance of each function varies based on the specific encounter and phase of care. More of all functions at every visit is not necessarily the ideal.
- Could have screening questions to determine if a function is relevant for a specific encounter (e.g., whether there was a decision to be made). If relevant, have questions specific to that function.
- One function may take precedence over other functions. Patients may be satisfied if one function is done well.
- A theoretical approach helps ensure that important elements are included in the model. Different theories can be tested when we have measures.
- Which theory is most relevant may differ by phase of care/ type of encounter; this can be empirically tested.
- Need for normative theory on how measures should be applied in different contexts; need expert consensus on what clinicians should be doing in terms of PCC in different contexts (e.g., at diagnosis, at end of life).

Decisions/Conclusions

- Retain the six original functions for now.
- At this point in the measurement development process, we need to be most concerned with ensuring that we are comprehensive with good measures for each function.
- Empirical testing is necessary to determine whether the functions make sense as distinct constructs, whether the model needs to be refined.
- Also need empirical testing to determine the relative importance of the functions at different points in cancer care.
- A theoretical approach has benefits but don't have information at this point to assess best fit theory.

Clinical Contexts and Other Considerations for Focusing Measurement

We discussed the care setting, types of providers, stages in cancer care continuum, and types of cancer.

Key Points Discussed

Care setting:

- A high proportion of cancer care occurs in small private practice settings (45% of oncology care is deliverable by a practice with 2 or less oncologists). Capturing the PCC experience in these types of community care settings is important.
- Consider integrated health partners and community cancer centers as clinical contexts.
- One tool will not be appropriate for all contexts. There could be a general measurement tool and then modules for specific clinical contexts.

Types of providers:

- Should all health care providers be responsible for all aspects of PCC? Or is the goal that the cancer care team as a whole addresses the patient's needs?
- If the team members' roles are working well then the patient doesn't need to distinguish who is doing what. The patient is the unit. At the patient level, the team has to meet the patient needs.
- However, don't want to let individual providers off the hook. Each profession should have a distinct set of required PCC competencies.
- In order to function well, there can't be any breaks in the chain of care and important to determine where there are breaks.
- Patients often do not perceive that there is a team of providers. Depending on the care setting, the size/members of the team vary.
- There are challenges in how to define/describe the team in a way that makes sense to patients

Stages in cancer care

- Don't exclude end-of-life and palliative care. Boundary between survivorship and end-of-life is not always clear.
- May be a distinct PCC model for end of life.
- Don't focus on continuum, but on degree of engagement with the healthcare system.
- Ideally measurement could be applied across whole spectrum. Then have modules for specific populations.

Types of cancer

- Measures should apply across all types of cancer
- However, the nature and extent of patients' interactions with the health care system (e.g., type of provider they see) depends on cancer type.

Decisions/Conclusions

- **Who will answer the survey?** Adults with a cancer diagnosis.
- **What will be the focus of the questions?** Focus on the six functions and on the care team as a whole. Can potentially have modules for different situations (e.g. different care settings)
- **Where will the surveys target (which clinical settings)?** All clinical settings as PCC should occur across wherever cancer care occurs.
- Generic questions are the priority; can potentially add modules for different situations.
- For the provider survey, the focus will be on physicians and physician extenders (nurse practitioners, physician assistants); don't include technicians (e.g. phlebotomists) as their role in PCC not defined.

Fundamental Measurement Issues and Challenges

We discussed the following measurement issues and challenges:

Issue #1: To what extent should measures assess perceptions of communication behaviors (i.e., report of the communication behaviors that occurred), evaluation of communication behaviors, or both?

Decisions/Conclusions

- Assess both perceptions and evaluation of communication behaviors.
- For each function, develop and test both evaluative and behavioral items (both may not be important for all functions).
- Develop one global evaluative item for each function.
- Patients can have difficulty reporting on specific behaviors unless the behavior is very memorable or critical.
- Framing and wording of items will be critical.

Issue #2: To what extent should measures assess the communication behaviors or characteristics of the exchange?

Decisions/Conclusions

- The difference between asking about a behavior (“Did doctor do X?”) and the interaction (Was the exchange X?) may be too subtle. Could phrase: “*During our discussion*, I was able to ask all of my questions”; “*During our discussion*, my doctor listened to me.”

Issue #3: What is the best approach to measuring PCC longitudinally over the continuum of care?

Key Points Discussed

- Ideally would measure PCC both prospectively and retrospectively.
- Habituation is an issue with longitudinal assessment.
- Need to think about recall period (is 6 months for CAHPS; with 7 days to 2 weeks get general recall but not specifics).
- Questions should be framed in terms of measurement periods (“chunks”) that are meaningful to patients:
 1. Awareness that “something is wrong,” screening and diagnostic process
 2. Bad news, further diagnostic testing
 3. Treatment discussion and planning
 4. Beginning of treatment
 5. Period of active treatment
 6. Evaluation of treatment effectiveness, decision making
 7. Depending on #6:
 - Transition to follow-up care, or
 - End-of -life care
- Could conduct cross-sectional survey in which patients identify their phase in care (measurement “chunk”); questions would differ depending on phase.

- A phase can involve one or more medical encounters (e.g., bad news/diagnostic testing occurs over several visits)

Decisions/Conclusions

- Use patient-defined phases of care (measurement “chunks”); these would be meaningful periods of cancer care experience from the patient experience.
- For population-level surveillance, can ask about last visit or a sentinel event.
- For organizational level, could examine cross-sectional data for patients at different phases.
- Core questions will be asked across all phases and some specific questions for a specific phase. Empirically evaluate the importance of the function across the phases.

Issue #4: What is the approach to measuring PCC with a team of cancer care providers?

Decisions/Conclusions

- Ask about the team and then additional questions about particular provider(s), e.g. one that stands out.

Issue # 5. What are the most suitable study designs and data collection methodologies?

Decisions/Conclusions

- Consider ways to use personal health records.
- With web-based survey can add questions based on care setting, type of cancer, etc..
- Consider how to link the provider and patient surveys.

Other Decisions:

- Begin with organizational-level assessment and then work up to population level surveillance.

Detailed Meeting Notes

Options for PCC Conceptual Model

Rick Street, PhD, Neeraj Arora (NCI), Ron Epstein, MD, Pam Williams-Piehota, PhD (RTI), and Tony Back, MD

1. Rick’s Model

Rick: We originally took a functional approach to the model. Functions extend beyond behavior and capture the interactive process. Should we measure what folks are doing or how well they’re doing them? There are a number of functional models. We identified these six functions as the most important. They are fairly distinctive but still related to one another. Communication is complex. The first (monograph) model was the “traffic jam” model (as Steve refers to it). We struggled with overlap. The Venn diagram showing overlap between functions makes it appear that exchanging information is the most critical.

My new “molecule” model or embedded model shows that embedded within each function is any other function. I thought about how functions may manifest themselves. For

example, with decisionmaking, we find that information exchange, responding to emotion, and managing uncertainty are embedded within it.

Or, we could have 6 subscales and then individual items that may draw on other functions. So often in self-reported options we ask about what the doctor was doing. But from a functional approach we might focus on the interaction itself – what the nature of the conversation was about.

Bryce: The model we choose will impact whether we will use a subscale score and overall summary score, ideally.

Ron: When we test the model empirically, items may fall along context (e.g., in the information exchange context) or along other lines.

Kathy: I suspect that empirically the model will be one factor. We just need to make sure that we cover everything that's important to include in the model and build a blueprint. Will patients discriminate? Does it matter if they do?

Bryce: Agreed. Capture what's important. Stick to good survey development principles (e.g., no double-barreled items) but there will be cross-loadings. We'll need to test and empirically determine the model. One option is to correlate items that load on different factors; build in correlations for cross-loadings. If we presented vignettes, related to context items on the vignette would cluster together (account for this) but also load on concepts.

Weighting is an important issue. Weights can be derived empirically. If items correlate more, weight empirically. I'd lean toward conceptual weighting (not empirical weighting). We struggled with this for the PROMIS project – do we develop a hierarchy or a framework? No one could agree on this, so we ended up with a framework that allowed us to measure each function really well. So, we can move the functions around in the framework without disrupting the conceptual model.

Neeraj: Measure them independently. Keep in mind the future empirical tests we'll conduct as we develop the model.

2. Ron Epstein's Model

Ron: My thoughts are based on my experience as a family doctor and palliative care doctor, and how the functions interact in these two different contexts. My view of theory is rather democratic. I think it is more contextually-constrained. We should be open to this shift. Since writing the monograph, I have a slightly different view on information exchange and decisionmaking. We tend to review information exchange as a commodity, but it's also actionable. Patients want action that they can put into use. Embedded-ness of domains assists with that a bit. There is a time element to it. (Quantity of information) more is not better. Is it at the right pace? There's a dynamic quality that's embedded in the relation between the information giver and receiver. Information is embedded in the interaction/information exchange.

Good decisions are sometimes non-decisions. Both parties may think that no decision needed to be made when they are in the same mind. Collaborative cognition (from the geriatrics literature) shows that decisions are made in the space between them (shared mind). This also has

an implication for autonomy. But you can't talk about independent decisions because people come to them together. Do shared minds represent shared illusions?

Clinical context is a clinical reality that we need to take into account. When stakes are the highest, patients' cognitive resources are the most diminished. People engage more in collaborative cognition and avoid decisions. An autonomous approach is less applicable in these situations.

Relationship infuses these functions more than indicated in the first (monograph) model. This would be a qualifier. Uncertainty is a relational quality. Relationships have more to do with any of the other functions than the other functions do.

Literacy – Those most disenfranchised from care can't understand items.

Tone deafness – These individuals can't parse apart pieces but know their doctor cares. What do you do to invoke their memory during measurement? You need a stem like "think back to last encounter with your doctor..."

Patients can't envision situations; they can only recall their own experience. So for measurement, perhaps show videos and ask "was your experience more like this (a) or like that (b)?"

There may be different psychometrics depending on each domain. This diversity is okay; it doesn't need to be a stable model.

Neeraj: we're focusing on self-report right now. From a measurement perspective, how would you see the contextual relationships?

Ron: You'd expect to see that if the relationship is rated poorly – no respect, etc. - then the other functions won't make sense. There's something deterministic about the relationship function.

Neeraj: If trust is the main thing we want to look at, should we move it higher hierarchically?

Ron: Then the relationship is iterative; trust is a precondition and an outcome. Can you deal with this empirically?

Eric: If my patient likes me, they would globally feel good about each of these domains. How can we build this into the methodology to get them to tease apart the domains? Prime them? Scenarios?

Ron: Evoke complexity science with medicine. I haven't seen measures of iterative-ness.

Neeraj: Use longitudinal measures and then we could test the recursive-ness of the models.

Eric: We could ask "How was it the day that you and your oncologist talked about your diagnosis?" This could provide an element of recall.

Kathy: I thought we would be measuring specific encounters, not the overall interactions. If we want to get information for quality improvement, we need to think about where we're going to get the most quality data. Things can really change, if you neglect to do something that's essential. Longitudinal data collection is essential. We need to think about validity. Are we

measuring what we are trying to measure and reflecting encounters? For self-management, we need to focus on post-encounter. That's a timing issue of when you measure.

Ron: Patients are incredibly forgiving.

Katherine: This argues for assessing both global evaluation and specific encounters.

Tony: We're struggling with these static qualities. I don't see the intentions of the patient and doctor going in. If they rate the importance of the six functions on the day they get diagnosed, for example, they are not focused on decisionmaking, and they're focused on emotions. More of all of these functions at every visit is not the best thing. It varies depending on the phase of care and the situations. The problem with the model is that it doesn't take into account the reality of the priorities for doctor and patient at each encounter. Patients would be looking for the doctor to do different things at different times. SF-36 for example does not capture the situation. Implicit in embedded-ness is that one function may take precedence over the other ones. Patients may be happy as long as one function is done well.

Neeraj: We could go with an episodic approach. We could frame items.

Tony: I see this as a conceptual issue. I bet trust is a function of cumulative experience. The patients would have more of a spread at the first visit than later on in the care. The patient has a sense that "the doctor knows what I mean". Over time does the importance of what happens medically fade?

Eric: Correlate whether goals were achieved.

Tony: Patients don't have many experiences with oncologists, so they are less discriminating. We need to set a high bar of what doctors should do.

3. Tony Back's Presentation

Tony: I covered most of my points already, but I have other points about language. Some language includes management strategies, which are clinician-driven, as opposed to measuring whether the doctor deals with them. I am concerned about measuring these management strategies that are entire fields themselves (e.g., managing and detecting depression). I don't think that are these communications functions. Communication gives you the ability to do this but doesn't mean we need to include them in PCC.

Ron: Explore the range of patient emotions, not treating depression as a disease.

Tony: Using emotion-focused management strategies is a doctor-centered view not a patient-centered view. Is there another way to deal with this?

My big point is to think about this timeline issue.

Bill: You may not need every function at every visit, but they may implicitly be there. Sometimes these implicit issues exist. Is there any way to capture this? One example is that

therapy should continue – it’s implicit but it’s never explicitly stated. Do we need to capture implicit functions?

Lauren: We could include a well-constructed screening question.

Bill: Was a decision made at a meeting? Patients may answer no.

Kathy: “I brought my side effects list and the doctor didn’t look at it.” These are a part of decisionmaking. The patient may not see it as decisionmaking, but we’ll capture it elsewhere.

Kristin: We, in surveys, push patients into roles. Patients have different desires. And in so much as their desires shift from a patient perspective, how much can they feel like they can do what they want to do? Action-ability is a stronger issue. People feel a pressure to change their role in the system.

Lauren: We need to have a companion campaign targeting doctors about patients’ roles in their health care.

4. Pam’s Presentation on Self-Determination Theory Applied to PCC Model

Neeraj and Ron: It’s the perception of choice that’s actionable. Measure choices and decisions, when possible.

Steve: The benefit is to do hypothesis testing to see if autonomy is clinically relevant.

Paul: I think we need a normative theory on how these measures should be applied in different contexts. We need a theory that says “In situation A, autonomy is more of a consideration. In situation B, X is more of a consideration.” We need a theory of how to apply these measures at different points. It’s a missing point.

Ron: This is more of a problem when you’re dealing with trajectory of a particular patient. It’s less important when doing population testing.

Paul: We all have normative assumptions. Some of these are non-issues and I worry about measuring and trying to put them on a scale. There may be misinterpretation of subsequent data. We need consensus from experts on what doctors need to do.

Murrey: Another piece of is that you also need to collect data from patients to inform what’s important in addition to expert input. We should really be informed from the data we collect as well.

Ron: Ask immediately post encounter, which function is most important to you today? If x then y items would be completed.

Bryce: Are there gold standards out there that can help us test which model is the best one? Think about the ways to assess the fit of the conceptual and empirical models? Are we thinking of a global concept or sub-domain level? It seems the answer is sub-domain. We could use

screening items to determine which items to tap into. Remember how we'll use the instrument and how we'll use it to develop interventions.

Lauren: This gets into mode of administration. Computer administration could easily calculate the screener scores that lead to questions to ask.

5. Neeraj's Presentation on Self-Regulation and Coping Theories Applied to PCC Model

Neeraj: When there's a health threat people engage in emotion and problem focused coping. Social support literature – how best can we provide instrumental, emotional, and cognitive support to patients? Uncertainty is a subfunction of each of the other functions (decisionmaking, self-management, responding to emotions, healing relationships). If we were to reduce overlap, I would remove uncertainty and embed it under others. Information exchange is the task for assessing each of the 4 remaining functions. Measure information exchange and uncertainty as part of the other 4 domains.

Murrey: Consider trust as an outcome. Trust is a broad issue that's contextually based; you may trust your caregiver but your communication needs may not be met. It's part of it but probably not the right outcome. We could measure some process and some outcome measures of the relationship. There would be certain elements of creating the relationship at different points in time.

Rick: Uncertainty is an important task of communication. Does it have a standalone value so we need to assess it to see if it's important? It's almost as though we need a model that all folks are happy with but that can have an autonomy support or a social support angle. Then we can frame it as folks want. I see the value of autonomy support and other contextual aspects of relationships.

Katherine: Is anything lost with this model (subsuming functions)?

Ron: Cognitive support is more than just decisionmaking. I think decisionmaking is overemphasized in this model. I don't think there are a lot of decisions to be made. More of it is management not big decisions. No communication is meaningful without some sense of respect. Autonomy support is a relational act. Should measure abstract relationships as well. This gives decisionmaking a primacy that it doesn't deserve. Some information exchange is sense-making not decisionmaking.

Eric: We need to keep functions separate b/c functions' importance over time is variable.

Ron: This could be a research question. We have SDT model, Rick's embedded-ness model, Neeraj's social support model—test items for each of them and empirically test them to see what falls out. Is a different theory most appropriate at the prevention phase, treatment phase, etc.?

Neeraj: Keep in mind that each function has other functions as pieces of them. Avoid redundancy in item development. Do we need the macro version or the context-specific version?

Paul: Information exchange could be more generic—the sense-making aspect. It’s a different level of specificity.

Rick: Measure work that needs to be done and work that needs to be done well – e.g., *quality* decisionmaking. Information exchange can be a particular act.

Ron: The domain of existential wellbeing is a stronger predictor of quality of life (QoL). Those things that we use to derive meaning may be a better predictor of outcome. Re-label “information exchange” as “finding meaning” perhaps.

Brad: I would fight against that. At the last meeting, we determined that all six functions are of value. *Prima facie*.

Clinical Contexts and Other Considerations for Focusing Measurement

Katherine Treiman, PhD (RTI) and Eric Nadler, MD

Eric: In the US, 45% of oncology care is deliverable by a practice with 2 or less oncologists, and 65% of care is delivered in the community.

Katherine: We recommend that we focus on NCI comp. cancer centers. They are more likely to work well with us, have fewer challenges. We are talking about patient and provider surveys, remember.

Katherine: In terms of types of care providers, we recommend medical oncologists, physician extenders.

Ron, Tony, Eric: A common but variable care model is medical oncologists, physician extenders, and a combination of care. Sample individual care providers or the medical team?

Eric: Each provider would have a different perspective on these domains.

Neeraj: This has implications for who you target for provider survey and for the patient survey, based on who the respondent is speaking to.

Brad: With *Crossing the Quality Chasm*, we decided to get input on the *team* of people. If all roles are working well then the patient doesn’t need to distinguish between them. When you get on a plane, you don’t distinguish whether the pilot was well-dressed. You evaluate more globally “Were they nice?” If you choose the wrong measure, you can really mess up because you would measure nurses meeting the doctor role, etc.

Eric: If you don’t parse out the roles, you may get very different answers.

The surveys will be designed for use in organizational-level quality assessment and for population-level surveillance.

Brad: The patient is the unit. Their perspective is what I care about. At the patient level, the team has to meet the patient needs.

Eric: It depends on the goal: is it that each and every doctor should be delivering PCC?

Tony: The value of measuring the individuals is that the doctor needs to realize the other needs of patients are not being met.

Brad: There is a lot of training for doctors imparting that you operate as a team and shouldn't bear the burden of all care.

Eric: Point out to surgeons that they may not be delivering PCC as well as they should.

Brad: In order to function, there can't be any breaks in the chain of care and you want to identify where the breaks were for optimal group functioning.

Steve: Consider integrated health partners as a context. Focus on where you really should be having those types of interactions across specialists. Community cancer centers are another area to focus on.

Bryce: Don't ask patients to differentiate who should be delivering which types of services. Simply ask "Did you get the information you need", not "Did the doctor give you the information that you need?" We can't develop one tool appropriate for all contexts. We need a more generic and broad way. Then develop a specific module for a specific context (e.g., surgery).

Neeraj: At an organization level, is it worthwhile to focus on an individual level?

Bill: The team may change over time at an organization. We are early enough in the measurement process that we may want to include that level of specificity, and later throw it out or see if it's relevant to only certain contexts.

Brad: There is a parallelism, at the organization level; you want to enable multiple levels of analysis.

Tony: Each profession needs their own set of competencies.

Ron: Let's not let doctors off the hook – for example, sending the nurse down the hall to deal with the patients' emotions. This could happen with the team approach. Set the ideal standard for doctors. Patients won't know what's missing unless we ask them.

Kathy: I think they do know. They talk to other patients and have their own sense. They say "what team?" They don't realize that they have a cancer team.

Eric: Some patients have more sophistication than others. In a one doctor setting, patients would have a different understanding of what to expect, and what it means to function well. There is heterogeneity of care delivery in the US.

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Kathy: If the focus is on the patient, it's not what we think is good or bad. We need to write the right items.

Neeraj: We need to give patients more credit.

Brad: It's all about how the patient perceives the system. To force my organization on them is what messes up my measurement. Measure through the patients' eyes.

Lauren: Prioritize the team. Then later could have a specific module for a specific context.

Ron: Don't use term "the people that provide your cancer care"

Lauren: We will define it.

Steve: It works well.

Bill: Ask on the screener "Were your needs met?" If yes, then attribute them (Did the doctor meet your expectations? Did the nurse? etc.?).

Ron: Be careful about issue of self-referral of patients to center settings.

Lauren: This is also true in community cancer centers.

Ron: Use the CCOPS network potentially. There will be different kinds of responses. When dealing with unsophisticated patients, you need to provide more guidance than folks that have been to 3 cancer centers.

Neeraj: Need a variety of representations in the cognitive testing. We want to assess overall team and also break it down further.

Ron: How do we want to define team – do we include phlebotomists, for example?

Kathy: Include chemotherapy nurses, too.

Neeraj: The purpose of provider survey is to see if we could we use the patient survey to come up with an equal and short form for providers. It's the interaction that we want to measure. We want to match them.

Ron: Measure the psychosocial interaction.

Kathy: That's more tied to research, not quality improvement.

Katherine: Stages in the cancer care continuum: we'll focus on diagnosis, treatment, post treatment/ survivorship.

Ron: I argue strongly for not excluding palliative care. The boundary between survivorship and palliative care is lessening. End of life is defined as 6 months expected survival.

Kathy: There's a transition out of care that's important. Survivorship.

Eric: I'm a lung cancer doc and 85% of patients with lung cancer die of it; so all of it is end of life management (palliative care).

Neeraj: We need boundaries.

Ron: We don't want to include those who are cured.

Tony: Start near time of diagnosis through active treatment as a chunk to start with. Here there's more contact with the patient care team.

Steve: I concur. Parse out treatment a bit more—initial treatment, adjuvant therapy. There are different issues, recall biases, and the cancer care team is different at different phases.

Brad: The holy grail of quality measures is something that could be employed across the entire perspective. Then develop measurement modules for specific populations. Patients could complete diaries at the end of visits. So many questions remain regarding the transition issue, for example. Good screening items would provide some level of measurement on all patients.

Neeraj: End of life deserves its own model. For hospice care, the doctor is not a key player any more.

Ron: Include those who are more active in the cancer care system.

Paul: We're getting hamstrung with the continuum. Define inclusion criterion as the extent or degree of engagement with the cancer care system.

Fundamental Measurement Issues and Challenges

RTI and Group Discussion

Issue #1: To what extent should measures assess communication behaviors, perceptions/evaluation of communication behaviors, or both?

Lauren: Behaviors or evaluations of behaviors – is one more likely to lend itself to ceiling effects?

Ron: We may need memory aid for communication behaviors like “In my last visit with my doctor...” Link perceptions to some kind of behaviors: “In my last visit, my doctor provided me with enough information...”

Rick: One problem with self-report: if an evaluation assessment predicts an evaluative outcome—there is some overlap. Is the assessment itself the outcome? Or is it distinctive from the outcome? If we are predicting affective measures from behavior, then that's okay. We can't use an evaluation to predict an evaluation.

Ron: We need to construct the right items. There are vast differences in the qualitative vs. quantitative literature on patient perspective. Use quantitative assessment to get qualitative-like data. Find some way to use their own words. Conduct analysis of their language.

Lauren: We can do this with web-based assessment.

Kathy: It's important how we frame it. Give them motivation to complete the survey.

Lauren: We need face-to-face rapport to do that, but we can move the survey one step closer.

Tony: Measure "What did the doctor do to actively connect with me?"

Neeraj: "Rate your doctor's level of knowledge of your cancer." A lot may depend on the context. I'm okay with behavior and perceptions.

Steve: From a quality improvement view, ask globally as well as "What did my doctor do that demonstrated interest in me?" Get at the behaviors.

Ron: I could use more information from my doctor about x, y, z. Frame in terms of what providers did not do well. (Ron cited example)

Tony: The Quality of Dying Scale is 0-10 with not a lot of anchors in between, so hard to rate. Skewed data.

Neeraj: We're not trying to achieve a normal curve in our responses. "Less than excellent" means there is something that can be improved.

Bill: Keep some of those broader items either positively- or negatively-framed. Think down the line. Can we take a screener approach and then ask more detailed questions? Test a number of items upfront. Then the problem can show up in the more detailed questions and give clues as to the effectiveness of the screener items.

Kathy: Ask patients about evaluation not behaviors. They don't do a good job of recording specific behaviors, unless we are really specific, memorable, and critical – be selective.

Rick: Assess what's important related to this function. "Does doctor do X? How important was that to you?"

Neeraj: Take each function and come up with both evaluative and behavioral items. Both may not be important for each function. Take it function by function. Include open-ended items in patient testing.

Answer: Both and it depends.

Issue #2: To what extent should measures assess the communication behaviors or characteristics of the exchange?

Rick: Focus on what doctor and patient did together.

Tony: Some patients may not distinguish between “my doctor did” and “my doctor and I did”.

Bill: There are multiple potential roles for measurement. If we are focused on population reporting, then broaden the measures.

Neeraj: The bigger issue is overall perception of team or individual provider. Answering this question makes it easier to answer others. If we are conducting organizational-level monitoring of PCC delivery, what would we ask patients?

Bill: Individual identification would help – which provider it was. Later we can expand to the team.

Tony: We will need some information on both. If the team does a bad job, where was the breakdown? Individuals or the system, for example?

Lauren: There are so many elements to quality measurement.

Tony: Patients value having someone on the team they can talk to.

Neeraj: This is the kind of question I can see including on navigation – “Did you have someone on the team you could talk to?” How deep do we go in terms of the team – doctors and physician extenders?

Tony: Doctors, mid-levels, nurses (chemo and oncologists) should be included but not techs b/c they haven’t been given a clear framework related to PCC and their jobs.

Kathy: Ask “Is there anybody else who was particularly important for your care?”

Rick/Steve: “During your last trip to the clinic, who did you see? Check all that apply. During that visit, how would you rate your care?” Let them designate.

Bryce: Note who you saw on your last visit. They form your team. Then have them rate each of them. Do this via computer format. Ask functions at the overall level and then 2-3 really focused questions at the end on care team.

Steve: “Was there anything that surprised you at your visit - good or bad?” Open-ended.

Paul: This way of measurement we’re discussing limits the patient-centeredness of it because of the care team assessment piece.

Ron: I'm worried about memory issues. "Think about your last visit to the cancer center. Who did you meet with?" Provide some global impression of individual. Then assess specific impression of each function. "Who is the person you interacted with most around this function?" That provides some way of weighting it.

Neeraj: List the six functions. "Who is most important for this?" Then have a few more generic items.

Rick: Pick a person that's most salient and then rate items for that team member.

Lauren: Acknowledge the team level. Three team members: physician, extender, nurse. Evaluative and behavioral generic questions for each measure. Then specific questions on 1 provider that stands out.

Ron: We don't have to ask everything, just indicators that show the most variability or that we judge as most sensitive to change or the most important.

Neeraj: Just asking about during your last visit (specific) is not going to work.

Tony: "Of all the people you saw today, did you get enough information?"

Katherine: On NCCP, we did this. We provided some examples of what we meant by team.

Issue #3: What is the best approach to measuring PCC longitudinally over the continuum of care?

Neeraj: Do both prospectively and retrospectively.

Lauren: Habituation issues. In CAHPS, 6 months is generally the recall period to reflect back on your care.

Katherine: Should we identify specific time points for assessment?

Ron: The bad news visit, but it usually doesn't happen in oncologist's office (precancer care).

Steve: Reflect back on bad news – no problem.

Tony: Query them on patient-defined chunks. 1 week would be good. 7 days.

Bryce: Consider EMA (ecological momentary assessment). They have pretty accurate recall that day. Past 7 days to 2 weeks, you get the general heuristic not specifics.

Kathy: This is more argument for perspective assessment not behaviors.

Issue #4: Measurement "Chunks"

1. Awareness that "something is wrong," screening and diagnostic process
2. Bad news, further diagnostic testing

3. **Treatment discussion and planning**
4. **Beginning of treatment**
5. **Period of active treatment**
6. **Evaluation of treatment effectiveness, decision making**
7. **Depending on #6:**
 - **Transition to follow-up care**
 - **End of life care**

Tony: We could conduct a cross-sectional study of everyone who walks into a clinic and let them identify where they are in the process. Have one set of questions for each chunk. There could be a core for each chunk.

Steve: It's important to find out the curability of their cancer. Get it from a registry or medical record. Patients will be confused; get it from the organizational level.

Steve: Ask new patients about screening/diagnosis.

Neeraj: #3 Chunk above could be one visit or multiple visits but within a relatively short time period. We could think across visits.” When you were making treatment decisions, did x....”

Steve: Should we measure people that are in the middle of the phase or after they've completed the phase?

Kathy: Let the patient manage the data collection. If recruited then let them have access to the reports of data, and have them complete it as appropriate. It's an empirical question: measure at end of every visit and see what data you get. Then go the other route and see what you get.

Issue # 5: What are the most suitable study designs and data collection methodologies?

Neeraj/Steve: The organizational level is the easier place to start. Then work up to population level.

Tony: For population level, drill down to assess a sentinel incident.

Neeraj: Web surveys might be the way to go.

Lauren: NCCP was multimodal; 8% responded via the Web. Mail was the most popular. Few responded by phone. In-person administration using a computer is the ideal but also the most expensive.

Whiteboard Recap and Decisions

Lauren:

- Can consider an embedded model, asking about a function within the context of another function (use subscales)
- The patient-clinician relationship suffuses the functions
- Relevance of the functions likely varies at each encounter (e.g. based on stage in cancer)

- Theories help ensure that important elements are included; can test different theories once have measures.
- We are sticking with the six functions. Focus on asking about the care team as a whole. Then go back and do modules by the care continuum and/or type of cancer. Generic questions are a priority. Core questions will be asked across all chunks and some specific questions for a specific phase. Core + specific questions for each chunk. Empirically evaluate the importance of the function across the chunks/phases.
- Don't let empirical results drive everything entirely. We need to start with some a priori conceptual view points, a normative model.

Rick and Tony: Existing literature will give us an idea of what to ask about more specifically for different measurement phases, especially phases #2 and 3 where most of the work has been done.

Steve: On the provider survey they answer in terms of about specific patients. Criticism of CANCORS is that we didn't ask doctors about the specific patients so responses could not be linked.

Street: That's more of a design issue not a survey issue.

Neeraj: We'll aim to create a blueprint of the provider survey from this project. More testing and work will be part of a subsequent contract.

Finalize the PCC Conceptual Model

RTI and Group Discussion

Neeraj: Keep the six functions for now. It is okay for them to be embedded, just don't create duplication. Empirically we may end up with 3 functions.

Rick: Empirically what we find may be different across phases of care ("chunks")

Next Steps

Neeraj: Think about the cognitive testing that we need to do. What do we really need to test before we go into data collection? We may need midcourse corrections.

Lauren: The next step is assembling the items, and a public call for measures. Then we'll consider issues just raised during this meeting. Then we will put them in preliminary instruments and fill in the gaps.

Lauren: Need to review the distinction between SEG and Expert Advisers

Neeraj: What do we want to send to stakeholders at this time? Send them the six functions and measurement phases ("chunks")?

Lauren: Then ask them what they need and how our work would fit in with their work.

Bill: We could potentially get some measures from them as well.

Appendix D. Objective 1: Summary of the PCC Functions and Domains

EXCHANGING INFORMATION

- Exploring Knowledge, Beliefs, and Information Needs and Preferences
- Sharing Information
- Providing Informational Resources and Helping Patients/Family Members Evaluate and Utilize Resources
- Facilitating Assimilation, Understanding, and Recall of Information

FOSTERING HEALING RELATIONSHIPS

- Discussion About Roles and Responsibilities
- Honesty, Openness, Disclosure
- Trust in Clinician's Technical Competence, Skills, and Knowledge
- Expression of Caring and Commitment
- Building Rapport, Connection and Respect

MANAGING UNCERTAINTY

- Constructing and defining uncertainty
- Assessing and understanding uncertainty (cognitive)
- Using emotion-focused management strategies (affective)
- Using problem-focused management strategies (behavioral)

RECOGNIZING AND RESPONDING TO EMOTIONS

- Expression of Emotions
- Exploring and Identifying Emotions
- Assessing Depression, Anxiety, or Psychological Distress
- Acknowledgement and Validation Emotions
- Expression of Empathy, Sympathy, and Reassurance
- Providing Tangible Help in Dealing with Emotions

ENABLING SELF-MANAGEMENT & PATIENT NAVIGATION

- Learning and Assessing
- Sharing and Advising
- Prioritizing and Planning
- Preparing, Implementing, and Assisting
- Arranging and Following-up
- Patient Navigation

MAKING DECISIONS

- Communication about Decisional Needs, Decision Support, and Decision Process
- Preparation for the Decision and Deliberation
- Making and Implementing a Decision and Action Plan

- Assessing Decision Quality and Reflecting on Choice

CROSSCUTTING FUNCTIONS

- Time for Communication
- Setting for Communication
- Communication about Team Roles and Coordination
- Basic interpersonal communication skills

Appendix E. Objective 2: Expert Advisors

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Appendix F. Objective 2: Initial PCC Functions and Domains

PCC Functions and Domains: Initial (March 15, 2010)

EXCHANGING INFORMATION

- **Exploring Knowledge, Beliefs, and Information Needs and Preferences**
 - Exploring, identifying, and expressing information preferences and needs (e.g., preferences for type/level of information, particularly for learning “bad news”)
 - Asking questions, expressing concerns, seeking information
 - Perceptions and judgments about whether provider encourages questions, information seeking
 - Exploring, identifying, and expressing knowledge and beliefs (e.g., related to causality, prognosis, treatment options, side effects, recurrence, self-care) and reasons for knowledge and beliefs
 - Discussing misinformation (e.g., sources, reasons for believing)
 - Perceptions and judgments about whether provider addresses and explains any misinformation
 - Acknowledging and discussing any differences of beliefs and opinions
- **Sharing Information**
 - Sharing information about cancer experience (“cancer story”), including experiences with diagnosis, cancer care, effects on quality of life, and barriers/facilitators for care
 - Perceptions and judgments about whether provider values learning patient’s “cancer story”
 - Perceptions and judgments about whether provider shares information in a way they can understand
 - Perceptions and judgments about whether provider shares information consistent with their preferences (e.g., for type and level of information, especially for “bad news”)
 - Perceptions and judgments about whether provider anticipates their information needs and provides relevant, useful information proactively
 - Perceptions and judgments about whether provider checked that information needs were met
- **Providing Informational Resources and Helping Patients/Family Members Evaluate and Utilize Resources**
 - Discussing sources used for cancer information (e.g., whether sources trustworthy)
 - Exploring and identifying need for informational resources and identifying suitable resources
 - Perceptions and judgments about assistance provided to evaluate information
 - Perceptions and judgments about information resources provided (e.g., whether relevant, easy to use, met their needs)

- **Facilitating Assimilation, Understanding, and Recall of Information**
 - Perceptions and judgments about whether information provided was appropriate for them (e.g., in terms of how easy to read, relevant to their situation)
 - Perceptions and judgments about whether provider shared information in a way that made it easy to understand and recall (e.g., used everyday language, graphics, visual aids, repetition, summarization, explanation of medical terms, writing down information).
 - Whether provider suggested using methods to enhance recall (e.g., audio-recording, taking notes, bring family member or care giver to appointment)
 - Perceptions and judgments about whether provider checked for understanding.

FOSTERING HEALING RELATIONSHIPS

- **Discussion About Roles and Responsibilities**
 - Discussion of expectations and preferences related to roles and responsibilities (e.g., roles in making decisions; role of family members and other caregivers)
 - Negotiation, clarification, confirmation of roles and responsibilities
 - Discussion of shared goals for cancer care
- **Honesty, Openness, Disclosure**
 - Perceptions and judgments about whether provider encourages disclosure
 - Disclosure, sharing complete and honest information (e.g., about health behaviors, compliance, barriers to compliance, other health care received)
 - Discussing preferences about receiving complete and honest information (e.g., about diagnosis, prognosis, “bad news”)
 - Perceptions and judgments about providers’ disclosure consistent with patient preferences
 - Perceptions and judgments about provider’s trustworthiness in terms of honesty
 - Perceptions and judgments about provider’s honesty about any errors, misinformation, or misunderstandings
 - Perceptions and judgments about provider’s trustworthiness in terms of ensuring confidentiality
- **Trust in Clinician’s Technical Competence, Skills, and Knowledge**
 - Perceptions and judgments about provider’s trustworthiness in terms of technical competence, skills, knowledge
 - Perceptions and judgments about provider’s ability to get things done in the health care system
- **Expression of Caring and Commitment**
 - Perceptions and judgments about provider’s commitment to their best interests
 - Perceptions and judgments about provider’s commitment to patient’s ongoing care (i.e. non-abandonment)

- Perceptions and judgments about provider's demonstration of caring (verbal and non-verbal)
- **Building Rapport and Connection**
 - Perceptions and judgments about whether provider knows and cares about them as an individual and as a "whole person" (not just as a patient)

MANAGING UNCERTAINTY

- **Constructing and defining uncertainty**
 - Exploring and identifying areas of uncertainty
 - Reducible vs. irreducible uncertainty
 - Distressing vs. non-distressing uncertainty
 - Potential impact and importance of uncertainty
 - Context for uncertainty (known vs. unknown)
 - Inquiring about unstated areas of uncertainty (provider)
 - Introducing uncertainty into situations where patient assumes certainty (provider)
- **Assessing and understanding uncertainty (cognitive)**
 - Acknowledging uncertainty
 - Clarifying sources/reasons for uncertainty (e.g., lack of information, conflicting information, validity of evidence, etc.)
 - Expressing (and confirming) understanding of sources/reasons for uncertainty
 - Discussing conflicting advice from different sources (provider)
- **Using emotion-focused management strategies (affective)**
 - Accepting irreducible uncertainty
 - Denying uncertainty/Choosing not to deal with uncertainty
 - Exploring, identifying, and expressing emotions that accompany uncertainty (e.g., anxiety, frustration)
 - Perceptions and judgments about provider's response to emotions associated with uncertainty
- **Using problem-focused management strategies (behavioral)**
 - Exploring and identifying preferences for dealing with uncertainty
 - Customizing approach to meet patient needs (provider)
 - Discussing and formulating a plan for dealing with uncertainty (i.e., decision tree, contingency plan)
 - Perceptions and judgments about plan for dealing with uncertainty
 - Identifying information needs related to uncertainty; Seeking further information and resources (e.g., educational materials, Internet sites)
 - Perceptions and judgments about provider's response to information seeking

RECOGNIZING AND RESPONDING TO EMOTIONS

- **Expression of Emotions**
 - Perceptions and judgments about whether provider accepts and encourages emotional expression
- **Exploring and Identifying Emotions**
 - Exploring and identifying emotions
 - Perceptions and judgments about whether provider understands their emotions
- **Assessing Depression, Anxiety, or Psychological Distress**
 - Asking and answering questions to assess depression, anxiety, other psychological conditions
- **Acknowledgement and Validation Emotions**
 - Perceptions and judgments about whether provider acknowledges and validates emotions
- **Expression of Empathy, Sympathy, and Reassurance**
 - Perceptions and judgments about whether provider is empathetic
 - Perceptions and judgments about whether provider is sympathetic
 - Expressing, identifying, clarifying need for reassurance (e.g., what are specific concerns about which they need reassurance?)
 - Perceptions and judgments about whether provider is reassuring (e.g., reassurance about health, as appropriate; about relationship and commitment to patient's care and best interests)
- **Providing Tangible Help in Dealing with Emotions**
 - Discussion and identification of tangible help for dealing with emotions and emotional adjustment (e.g., counseling)
 - Medication prescriptions and/or referrals to support groups, counseling, therapy, and other assistance as appropriate
 - Development an action plan to get the help they need to deal with emotions and emotional adjustment
 - Perceptions and judgments about tangible help in dealing with emotions (e.g., whether resources and referrals are useful and relevant)

ENABLING SELF-MANAGEMENT & PATIENT NAVIGATION

- **Learning and Assessing**
 - Discussion of areas in which patients is interested in/motivated to change behavior,, barriers/concerns they have, confidence in undertaking the change, and their resources for doing so.
 - Discussion of areas in which help is needed for self-management
 - Discussion of patient's needs and desires (medical, social, financial, psychological including depression status) relevant to self-management.

- Perceptions and judgments about whether provider understands and addresses their information and other needs relevant to self-management
- **Sharing and Advising**
 - Sharing what is important as a patient including values and preferences for self-care and surveillance and health habits
 - Sharing impact that condition(s) or changes in condition have on patient's life
 - Bringing problems about condition or care to the provider's attention
 - Seeking information needed to collaboratively set goals or develop a plan with providers
 - Perceptions and judgments about whether provided helped to support patient autonomy
 - Perceptions and judgments about whether provide taught them what they "can do"
 - Perceptions and judgments about whether provider shared information appropriate for setting goals and developing a plan
- **Prioritizing and Planning**
 - Perceptions and judgments about whether provider helps them with tracking and monitoring condition and changes in condition
 - Discussing and making decisions collaboratively about goals and plans
 - Discussion to ensure understanding of the plan (specific steps, timeframe, role of patient, family and provider)
 - Perceptions and judgments about whether provider confirmed understanding of the goal and plans
- **Preparing, Implementing, and Assisting**
 - Learning and practicing self-care skills (e.g., symptom management, administering medications, adhering to schedule, dealing with stress, etc.); discussing challenges
 - Perceptions and judgments about provider's teaching of self-care skills and addressing challenges
 - Practicing techniques to aid recall and understanding of information, instructions and skills
 - Perceptions and judgments about tools and resources provided to support self-management
 - Perceptions and judgments about provider's follow-up with patient about implementation of self-management plan (e.g., success, failures, challenges)
 - Perceptions and judgments about provider's help in problem solving to facilitate self-management (e.g. addressing barriers, suggesting resolutions)
- **Arranging and Following-up**
 - Seeking assistance in communicating with other members of the cancer care team
 - Perceptions and judgments about whether provider facilitates communication with others on cancer care team
 - Perceptions and judgments about the provider linking them to outside resources (e.g. in community or healthcare system) and following up with patient about experience with these linkages

- Discussion about the need for mid-course corrections to plan
- Sharing information about what is working well, what is not, and new preferences/values based on experience
- **Patient Navigation**
 - Sharing information related to patient navigation (e.g., information about types of assistance available)
 - Addressing barriers to care
 - discussion of barriers to care including financial (e.g. insurance, welfare, disability)
 - perceptions and judgments about provider's assistance to address barriers to care (e.g., linking patient to support, services)
 - Discussion of cultural and language barriers to care
 - Perceptions and judgment about how provider addresses cultural and language barriers to care
 - Overcoming health systems barriers
 - Perceptions and judgments about how provider addresses health care systems barriers (e.g. facilitating appointments, follow-up, referrals)
 - Perceptions and judgments about how provider facilitates coordination of care

MAKING DECISIONS

- **Communication about Decisional Needs, Decision Support, and Decision Process**
 - Exploring, identifying, and expressing preferences for level of involvement (and family member/caregiver's level of involvement) in decision-making process (and who takes responsibility for choices)
 - Discussion of expectations for communication related to decision making (e.g., mode of communication, level of detail)
 - Seeking and discussing information to support decision making (e.g., about options, risks, benefits, probabilities)
 - Sharing information to support decision making (e.g., values, preferences, experiences)
 - Exploring, identifying, and expressing other support needed for decision making (e.g., psychological support, decision aids, coach, navigator)
 - Perceptions and judgments about whether provider shared information for decision-making
- **Preparation for the Decision and Deliberation**
 - Perceptions and judgments about whether provider let them know when there were choices and decisions to be made
 - Asking questions and discussing to confirm understanding of different options and their pros/cons
 - Perceptions and judgments about whether provider checked to ensure patient understanding of the choices
 - Clarifying and expressing opinions, values, and preferences related to different options
 - Perceptions and judgments about whether provider understands patient's preferences and values related to different options

- Exploring, identifying, and expressing certainty (or uncertainty) about options and choices and direction one is leaning in and why
- Perceptions and judgments about whether provider addressed areas of uncertainty
- Discussing health care provider's recommendation and opinions (including uncertainties)
- Perceptions and judgments about provider's discussion about recommendation (e.g. explanation of reasons for recommendation, whether explained any medical guidelines, evidence)
- Exploring and discussing reactions to recommendation, any differences of opinion, decisional conflict/ambivalence anxiety, doubts, questions
- Perceptions and judgments about deliberation (e.g., whether helpful in making decision)
- **Making and Implementing a Decision and Action Plan**
 - Provider asks about patient's choice (or if would prefer family member, other caregiver, or provider to make choice)
 - Exploring and discussing implications of choice and next steps
 - Perceptions and judgments about discussion of choice (e.g. whether provider confirmed patient's understanding of choice and implications of choice).
 - Discussion of implementation of choice (e.g. how to address potential barriers)
- **Assessing Decision Quality and Reflecting on Choice**
 - Sharing experience implementing plan (e.g., ease/difficulty of implementing, barriers)
 - Discussing outcomes of decision (e.g., effects on quality of life)
 - Expressing satisfaction with/other perceptions about choice (e.g., whether made "right decision," regrets, blame)
 - Expressing satisfaction with/other perceptions about participation in decision making (e.g., whether as involved as wanted to be)
 - Discussing whether/how to revise/build on prior choice/plan

CROSSCUTTING FUNCTIONS

- **Time for Communication**
 - Sufficient time for communication
 - Good use of time
- **Setting for Communication**
 - Privacy
 - Lack of interruptions
 - Quiet
- **Communication about Team Roles and Coordination**
 - Explains and clarifies roles and responsibilities of different members of cancer care team in patient's care
 - Communication about coordination among clinicians
- **Basic interpersonal communication skills**
 - Not interrupting
 - Paying full attention
 - Listening attentively

Appendix G. Objective 2: PCC Instrument Inventory

Name of the instrument (Name of instrument, scale or questionnaire, if it is known)	To be reviewed (Y/N) (Instrument to be reviewed in the inventory process)	Instrument Reviewed (Y/N) (Indicates review is complete)	Authors (This column is used to acknowledge scale or measure authors where they are known)	Citation (This column is used to indicate the citation of the article discussing the scale or presenting the findings related to PCC)	Notes (This column is used to provide any notes on the articles that may be helpful in evaluating the PCC scales and articles)	Included in the PCC Monograph (Y/N)
The Satisfaction with Decision Scale	N	N	Developed by Holmes-Rovner, Schmitt, Breer, Rothert, Padonu, Talarczk	Holmes-Rovner, M., Schmitt, N., Rovner, D.R., Breer, M.L., Rothert, M.L., Padonu, G., Talarczyk, G. (1994) Patient satisfaction with health care decisions: the satisfaction with decision scale. <i>Medical Decision Making</i> , 16, 58-64.	(See appendix in article) The scale contains six items.	N
Study evaluating patient evaluation of physician behaviors and preferences for receiving bad news.	Y	Y		Fujimori, M., Akechi, T., Morita, T., Inagaki, M., Akizuki, N., Sakano, Y., et al. (2007). Preferences of cancer patients regarding the disclosure of bad news. <i>Psycho-Oncology</i> , 16(6), 573-581.	(See tables 2 and 4) Developed a scale based on the literature and studied what factors are most and least preferred by patients in communication regarding bad news about cancer care.	N
Scale developed by first by Sutherland et al. (1989) & revised by Degner (Bilodeau and Degner)/ Decisional Role Preferences	N	N		Mallinger, J.B., Shields, C.G., Griggs, J.J., Roscoe, J.A., Morrow, F.R., Rosenbluth, R.J., Lord, R.S., Gross, H. (2006) Stability of decisional role preference over the course of cancer therapy. <i>Psycho-Oncology</i> , 15, 297-305.	(Decisional role preference in Table 2.) Scale classifies decision making style of a five-point scale, from active (1) to passive (5)	N
RWJF Diabetes Patient Survey	Y	Y	RTI International			N
RCS-O (Relational communication scale for observational measurement of doctor-patient interactions)	N	N		Gallagher, T.J., Hartung, P.J., Gregory, S.W., (2001) Assessment of a measure of relational communication for doctor-patient interactions. <i>Patient Education and Counseling</i> , 45, 211-218.	(See appendix in article) 34 item doctor-patient relational communication scale adapted from its survey research form [Commun Monogr 1987; 54:307]	N
Practice Survey- UNC Health Care (Press Ganey)	N	N		http://www.unhcsbenefits.com/quality_safety/qualitymeasures/lnpt_survey.pdf	Section C. Your Care Provider- is most relevant.	N

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Name of the instrument (Name of instrument, scale or questionnaire, if it is known)	To be reviewed (Y/N) (Instrument to be reviewed in the inventory process)	Instrument Reviewed (Y/N) (Indicates review is complete)	Authors (This column is used to acknowledge scale or measure authors where they are known)	Citation (This column is used to indicate the citation of the article discussing the scale or presenting the findings related to PCC)	Notes (This column is used to provide any notes on the articles that may be helpful in evaluating the PCC scales and articles)	Included in the PCC Monograph (Y/N)
Perceived Decision Control Questionnaire	N	N	Legg England and Evans	Legg England, S., Evans, J. (1992) Patients choices and perceptions after an invitation to participate in treatment decisions. <i>Social Society and Medicine</i> , 34 (11) 1217-1225.	(Table 4 in article) Article also mentions a Health Control Questionnaire- developed by this author. Reference at time of article indicates it was submitted for publication, but I cannot locate instrument.	N
Patient-Practitioner Orientation Scale (PPOS)	Y	Y	Krupat (?)	Krupat, E., Rosendranz, S.L., Yeager, C.M., Barnard, K., Putnam, S.M., Inui, T.S. (2000) The practice orientations of physicians and patients: the effect of doctor-patient congruence on satisfaction. <i>Patient Education and Counseling</i> . 39, 49-59.	Suggested by a SEG member as a useful scale to look at the orientation of communication and control in the physician-patient relationship. The scale measures whether the relationship is more patient or physician controlled.	Y
Patient Preferences for Participation in Treatment Decision Making scale	N	N		Mallinger, J., Shields, C., Griggs, J., Roscoe, J., Morrow, G., Rosenbluth, R., et al. (2006). Stability of decisional role preference over the course of cancer therapy. <i>Psycho-Oncology</i> , 15(4), 297-305.	(Table 2) This article uses the Patient Preferences for Participation in Treatment Decision Making scale and a variety of other measures to evaluate change in preferences over time.	N
Patient preference was measured by the statement "I prefer to leave decisions about my medical care up to my doctor"	N	N		Arora, N.K., McHorney, C.A., (2000) Patient preferences for medical decision making: Who really wants to participate? <i>Medical Care</i> . 38 (3) 335-341	(This item is included in the report)	N
Patient -Doctor Interaction Scale (PDIS) (or AKA the Smith-Falvo patient satisfaction questionnaire)	N	N	(Smith-Falvo (?))	Bowman, M.A., Herndon, A., Sharp, P.C., Dignan, M.B. (1992) Assessment of the Patient-Doctor Interaction Scale for measuring patient satisfaction. <i>Patient Education and Counseling</i> , 19, 75-80.	(See appendix in article). Also mentioned in the article: the Medical Interview Satisfaction Scale, the Patient Satisfaction Scale of Linder-Pelz. Not deemed critical for initial review, so this instrument was skipped.	Y

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Name of the instrument (Name of instrument, scale or questionnaire, if it is known)	To be reviewed (Y/N) (Instrument to be reviewed in the inventory process)	Instrument Reviewed (Y/N) (Indicates review is complete)	Authors (This column is used to acknowledge scale or measure authors where they are known)	Citation (This column is used to indicate the citation of the article discussing the scale or presenting the findings related to PCC)	Notes (This column is used to provide any notes on the articles that may be helpful in evaluating the PCC scales and articles)	Included in the PCC Monograph (Y/N)
Patient Activation Measure (PAM)	N	N	Judy Hibbard and University of Oregon	Greene, J., Hibbard, J., Tusler, M., University of Oregon (2005). How much do health literacy and patient activation contribute to older adults' ability to manage their health? <i>AARP Public Policy Institute</i> .	(See appendix in article)	N
Outpatient survey-script- FY09	N	N	H. Lee Moffitt Cancer Center and Research Institute--FY09		Have instrument- unable to find actual source.	N
No name (Questionnaire)	Y	Y	Rebecca G. Hagerty, Phyllis N. Butow, Peter A. Ellis, Elizabeth A. Lobb, Susan Pendlebury, Natasha Leighl, Craig MacLeod, and Martin H.N. Tattersall	Hagerty, R., Butow, P.N., Ellis, P., Lobb, E.A., Pendlebury, S., Leighl, S., MacLeod, Tattersall, M.H.N. (2005) Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. <i>Journal of Clinical Oncology</i> , 23 (6) 1278-1288.	(Tables in article)	Y
No name (Questionnaire)	Y	Y	Sukdev Nayak, Jeeta Parija B. Pradhan, Suresh Reddy, J. Lynn Palmer, Tao Zhang and Edwardo Bruera	Nayak, S., Pradhan, J.P.B., Reddy, S., Palmer, J.L., Zhang, T., Bruera, E., (2005) Cancer patients' perception of the quality of communication before and after the implementation of a communication strategy in a regional cancer center of India. <i>Journal of Clinical Oncology</i> , 23 (21) 4771-4775.	(Table 1 in article) The questionnaire consisted of 8 questions prompting yes or no answers.	Y
No name (Patient preference for level of information desired if diagnosed with cancer)	N	N		Ajaj A, Singh, M.P., Abdulla, A.J.J. (2001) Should elderly patients be told they have cancer? A questionnaire survey of older people. <i>British Medical Journal</i> . 1323: 1160.	(Overview of questions asked, no formal instrument); will not be reviewed as no instrument is available.	Y

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Name of the instrument (Name of instrument, scale or questionnaire, if it is known)	To be reviewed (Y/N) (Instrument to be reviewed in the inventory process)	Instrument Reviewed (Y/N) (Indicates review is complete)	Authors (This column is used to acknowledge scale or measure authors where they are known)	Citation (This column is used to indicate the citation of the article discussing the scale or presenting the findings related to PCC)	Notes (This column is used to provide any notes on the articles that may be helpful in evaluating the PCC scales and articles)	Included in the PCC Monograph (Y/N)
No name (focuses on ratings of helpfulness and favorability of procedures in cancer diagnosis.)	N	N		Sardell, A.N., Trierweiler, S.J. (1993) Disclosing the cancer diagnosis: Procedures that influence patient hopefulness. <i>Cancer</i> , 72 (11) 3355-3365.	(Table 1 includes procedures leading to helpfulness ratings) Coding of interviews with patients and physicians; will not be reviewed as no instrument is available.	Y
No name (focuses on Health Professionals' Skills, Self-efficacy and Outcome Expectancies When Communicating with Cancer Patients)	Y	Y		Parle, M., Maguire, P., Heaven, C. (1997) The development of a training model to improve health professionals' skills, self-efficacy and outcome expectancies when communicating with cancer patients. <i>Society Science and Medicine</i> , 44 (2) 231-240.	(Table 2 includes communication behaviors that demonstrate good communication) The aim of this paper is to develop a conceptual model of communication behaviour in the cancer setting. The model aims to take account of the role that knowledge and skill deficits, self-efficacy and outcome expectancy beliefs and perceived support plays in the ability and willingness of health professionals to assess their patients' concerns	Y
No name (focus groups)	N	N		Curtis, J.R., Patrick, D.L. (1997) Barriers to communication about end-of-life care in AIDS patients. <i>Journal of General Internal Medicine</i> , 12, 736- 741.	(Will not be reviewed as no instrument is available.) Based on a set of focus groups and interviews conducted with patients and physicians about barriers to discussing end of life issues. Given that the article focuses on the outcomes of several focus groups rather than a survey instrument, it was not reviewed.	Y
No name (consultation satisfaction questionnaire)	N	N	Richard Baker	Baker, R. (1990) Development of a questionnaire to assess patients' satisfaction with consultations in general practice. <i>British Journal of General Practice</i> , 40, 487-490.	Not deemed high priority for the initial review of items.	Y

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No name (coding of interactions between patients and physicians)	N	N	Richard Baker	Street, R., & Gordon, H. (2008). Companion participation in cancer consultations. <i>Psycho-Oncology</i> , 17(3), 244-251.	Study uses coding of information exchange using the Street Active Patient Participation coding scheme. Provides information on communication priorities of patients and their companions.	N
No name - (Instrument to measure resources and support for chronic illness self-management)	Y	Y		McCormack, L.A., Williams-Piehot, P.A., Bann, C.M., Burton, J., Kamerow, D.B., Squire, C., Fisher, E., Brownson, C.A., Glasgow, R.E. (2008) Development and validation of an instrument to measure resources and support for chronic illness self-management: a model using diabetes. <i>The Diabetes Educator</i> , 34 (4) 707-718.	(Table 2 in article)	N
No name - (A 30-item scale evaluating cancer communication and decision making)	Y	Y		Siminoff, L.A., Rose, J.H., Zhang, A., Zyzanski, S.J. (2006) Measuring discord in treatment decision-making; progress toward development of a cancer communication and decision-making assessment tool. <i>Psycho-Oncology</i> , 15, 528-540	(Table 2 in article)	N
Medical Interview Satisfaction Scale (MISS)	N	N	Matthew H. Wolf, Samuel M. Putnam, Sherman A. James, and William B. Stiles.	Wolf, M.H., Putnam, S.M., James, S.A., Stiles, W.B. (1978) The Medical Interview Satisfaction Scale: development of a scale to measure patient perceptions of physician behavior. <i>Journal of Behavioral Medicine</i> . 1 (4) 391-401.	This is a satisfaction scale and so will not be reviewed in this round of the inventory.	Y
Measure of Patients' Preferences (MMP) questionnaire	Y	Y		Chiu, L., Lee, W. D., Gao, F., Parker, P.A., Ng, G., Toh, C. (2006) Cancer patients' preferences for communication of unfavorable news: an Asian perspective. <i>Support Care Cancer</i> , 14, 818-824.	(Table 3 in article)	N

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Measure for Patients Preferences (MPP) - Japanese version	Y	Y		Fujimori, M., Parker, P., Akechi, T., Sakano, Y., Baile, W., & Uchitomi, Y. (2007). Japanese cancer patients' communication style preferences when receiving bad news. <i>Psycho-Oncology</i> , 16(7), 617-625.	(See table 2) Conducts evaluation of the MPP-J scale using a sample of patients. Also evaluates the factor structure of the measure along with correlates using structural equation modeling.	N
Information Needs Questionnaire (INQ) and Control Preferences Scale (CPS)	Y	Y		Beaver, K., & Booth, K. (2007). Information needs and decision-making preferences: Comparing findings for gynaecological, breast and colorectal cancer. <i>European Journal of Oncology Nursing</i> , 11(5), 409-416.	(INQ in Figure 1; CPS in Figure 2) Provides information on patient preferences for information and preference control. This reinforces work already done with the PCC paradigm.	N
Health Information National Trends Survey (HINTS)	Y	Y	National Institutes of Health-Department of Health and Human Services			N
GHQ measure of psychological morbidity and The Patient Satisfaction with Communication Questionnaire (PSCQ)	N	N		Shilling, V., Jenkins, V., Fallowfield, L. (2003) Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for clinicians improve satisfaction? <i>Psycho-Oncology</i> , 12, 599-611.	(See appendix A in article) The PSCQ was based on the 51 item PSQIII- developed by Ware (Ware and Snyder 1975; Ware et al., 1983). This is a satisfaction scale and so will not be reviewed in this round of the inventory.	Y
Form II of the Patient Satisfaction Questionnaire (PSQ)	N	N	Form II of the PSQ was developed by Ware, Snyder, Wright and Davies	Ware, J.E., Snyder, M.K., Wright, W.R., Davies, A.R. (1983) Defining and measuring patient satisfaction with medical care. <i>Evaluation and Program Planning</i> , 6, 247-263.	(Table 1 in article) This is a satisfaction scale and so will not be reviewed in this round of the inventory.	Y
Family Evaluation of Hospice and Palliative Care	N	N	National Hospice and Palliative Care Organization			N

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Connect Instrument	N	N	Developed by Haidet, O'Malley, Sharf, Gladney, Greisinger and Richard Street	Haidet, P., O' Malley, K.J., Sharf, B.F., Gladney, A.P., Greisinger, A.J., Street, R.L. (2008) Draft Manuscript for submission- Characterizing explanatory models of illness in healthcare: development and validation of the Connect instrument. Submitted to Patient Education and Counseling.	(Patient version as appendix in manuscript) The instrument is 19 items that focus on six dimensions of explanatory models	N
Communication Quality Questionnaire	Y	Y	Stewart A.L. et al Milbank Q 1999; 77: 305-39.	Stewart, A.L., Napoles-Springer, A. M. (1999) Interpersonal processes of cancer in diverse populations. <i>Milbank Quarterly</i> , 77 (3) 305-339.		N
Interpersonal Style Questionnaire	Y	Y	Stewart A.L. et al Milbank Q 1999; 77: 305-39.	Stewart, A.L., Napoles-Springer, A. M. (1999) Interpersonal processes of cancer in diverse populations. <i>Milbank Quarterly</i> , 77 (3) 305-339.		N
Communication Assessment Tool (CAT)	Y	Y	Gregory Makoul, Edward Krupat, Chih-Hung Chang	Makoul, G., Krupat, E., Chang, C. (2007). Measuring patient views of physician communication skills: development and testing of the Communication Assessment Tool. <i>Patient Education and Counseling</i> , 67, 333-342.	(See appendix in article)	N
CanCORS Patient Survey	Y	Y	Dana Farber/ Harvard Cancer Center 1994			N
CAHPS Hospital Survey	Y	Y	Center for Medicaid and Medicare Services			N
CAHPS Health Plan Survey 4.0 Adult Commercial Questionnaire	Y	Y				N
CAHPS Clinician and Group Survey-Adult Primary Care Questionnaire	Y	Y				N

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Audio recordings analyzed	N	N		Liang, W., Kasman, D., Want, J.H., Yuan, E.H., Mandelblatt, J.S. (2006) Communication between older women and physicians: preliminary implications for satisfaction and intention to have mammography. <i>Patient Education and Counseling</i> , 63, 387-392		N
Assessment of Patients' Experience of Cancer Care (APECC) Study	Y	Y	National Cancer Institute and Northern California Cancer Center			N
Assessment of Chronic Illness Care (ACIC)	Y	Y	Bonomi, Wagner, Glasgow, VonKorff	Bonomi, A.E., Wagner, E.H., Glasgow, R. E., VonKorff, M. (2002) Assessment of Chronic Illness Care (ACIC): A practical tool to measure quality improvement. <i>Health Services Research</i> , 37 (3) 791-820).	(See appendix in article) (Rick - self management support part). Not eligible, organizational assessment by organization teams	N
	N	N		Geiser, F., Bijani, J., Imbierowica, K., Conrad, R., Liedtke, R., Schild, H., Schuller, H. (2006) Disclosing the cancer diagnosis: what contributes to patient satisfaction? <i>Onkologie</i> , 29, 509-513.		N
	N	N		Mandelblatt, J., Kreling, B., Figueiredo, M., Feng, S. (2006) What is the impact of shared decision outcomes for older women with breast cancer? <i>Journal of Clinical Oncology</i> , 24 (30) 4908-4913.		N
Patients Perceptions of Physicians' Informativeness	Y	Y		Street, R.L., Gordon, H., Haidet, P. (2007) Physicians' communication and perceptions of patients: Is it how they look, how they talk, or is it just the doctor? <i>Social Science and Medicine</i> , 65, 586-598.	This is the same scale as found in Street, R (1991) Medical Care - Volume 29 - Issue 11 - pp 1146-1152)	N

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No name - (Group of patient and physician questionnaires)	Y	Y		Brown, R.F., Butow, P.N., Boyle, F., Tattersall, M.H.N. (2007) Seeking informed consent to cancer clinical trials; evaluating the efficacy of doctor communication skills training. <i>Psycho-Oncology</i> , 16, 507-516.	(Table 5 in article contains items)	N
Krantz Health Opinion Survey	Y	Y	David S. Krantz	Krantz, D.S., Baum, A., Wideman, M. (1980) Assessment of preferences for self-treatment and information in health care, <i>Journal of Personality and Social Psychology</i> , 39 (5) 977-990.	(Table 1 in article)	Y
Health Care Professional Survey (HCP)	Y	Y		Roberts, C., Benjamin, H., Chen, L., Gavigan, M., Gesme, D.H., McCarthy, P., Samuels, R. J., Baile, W.F., (2005) Assessing communication between oncology professionals and their patients. <i>Journal of Cancer Education</i> , 20, 113-118.	(Tables 1-3 in article) This survey was administered on line at ConversationsInCare.com. Not eligible, health professional survey, N/A at this stage of project.	Y
Perceived Involvement in Care Scale (PICS)	Y	Y	Caryn E. Lerman	Lerman, C.E., Brody, D.S., Caputo, G.C., Smith, D.G., Lazaro, C.G., Wolfson, H.G. (1990) Patients' perceived involvement in care scale: relationship to attitudes about illness and medical care. <i>Journal of General Internal Medicine</i> , 5, 29-30.	(Table 1 in article and also located separately in share) Scale consists of 13 items	Y
Perceived Involvement in Care Scale (PICS)	Y	Y	Brody et al and Lerman et al)			N
Communication and Attitudinal Self-Efficacy (CASE) scale	Y	Y	Michael S. Wolf, Chih-Hung Chang, Terry Davis, Gregory Makoul	Wolf, M.S., Chang, C., Davis, T., Makoul, G. (2005) Development and validation of the Communication and Attitudinal Self-Efficacy Scale for Cancer (CASE-cancer). <i>Patient Education and Counseling</i> , 57, 333-341.	(Table 2 in article) The REALM (Rapid Estimate of Adult Literacy in Medicine) was used to determine the performance across literacy levels.	Y

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Uses RAIS to evaluate patient and physician communication about EMR data in the primary care setting	N	N		Margalit, R.S., Roter, D., Dunevant, M.A., Larson, S., & Reis, S. (2006). Electronic medical record use and physician-patient communication: An observational study of Israeli primary care encounters. <i>Patient Education and Counseling</i> , 61 (1), 134-141.	This is very similar to other articles on the topic. There is no new content or measurements here, but it does reinforce the basic PCC concepts by highlighting various types of communication and the functional purpose for this communication.	N
Physician's Humanistic Behaviors Questionnaire (PHBQ)	Y	Y		Weaver, M.J, Walker, D.J., Degenhardt, E.F. (1993) A questionnaire for patients' evaluations of their physicians' humanistic behaviours. <i>Journal of Internal Medicine</i> , 8, 135-139.	This instrument was referenced in the article. NEED TO ORDER THIS ARTICLE.	N
Patient perception of patient-centeredness (2A)	Y	Y		This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. <i>Patient Education and Counseling</i> , 35, 161-176. .	We are unable to locate this scale. They are referenced in the Boon article but no citation is provided.	N
Patient assessment/ physician assessment (2B)	Y	Y		This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. <i>Patient Education and Counseling</i> , 35, 161-176. .	We are unable to locate this scale. They are referenced in the Boon article but no citation is provided.	N
Control Preferences Scale (CPS)	N	N		Hawley, S.T., Lantz, P.M., Janz, N.K., Salem, B., Morrow, M. Schwartz, K., Liu, L., & Katz, S.J. (2007). Factors associated with patient involvement in surgical treatment decision making for breast cancer. <i>Patient Education and Counseling</i> , 65 (3), 387-395.	(Scale found in other articles) Need to obtain the CPS from other articles and review.	N

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Communicator Style Measure	Y	Y	Norton, R.W. (1978) Foundation of a communication style construct. <i>Hum Commun Res</i> , 4, 99-112.	Buller, M.K., Buller, D.B. (1987) Physicians' communication style and patient satisfaction. <i>Journal of Health and Social Behavior</i> , 28, 375-388.	This is the same as the scale in row 62. It is not applicable for inclusion in the inventory as it measures individuals' preferences and self assessment of preferences, does not measure interaction. This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. <i>Patient Education and Counseling</i> , 35, 161-176.	N
Interpersonal Communication Satisfaction Scale	Y	N	Norton, R.W. (1978) Foundation of a communication style construct. <i>Hum Commun Res</i> , 4, 99-112.	Buller, M.K., Buller, D.B. (1987) Physicians' communication style and patient satisfaction. <i>Journal of Health and Social Behavior</i> , 28, 375-388.	Unable to locate this item.	N
	Y	Y		Buller, Jr., D.B., Street, R.L. (1991) The role of perceived affect and information in patients' evaluation of health care and compliance decisions. <i>Southern Commun J.</i> , 56, 230-237.	This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. <i>Patient Education and Counseling</i> , 35, 161-176. .	N

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	Y	N	Street R.L., Wiemann J.M. (1987) Patient satisfaction with physicians' interpersonal involvement, expressiveness, and dominance. In M.L. McLaughlin (Ed.), Communication yearbook 10 (pp. 591-612). Beverly Hills, CA: Sage.	Buller, Jr., D.B., Street, R.L. (1991) The role of perceived affect and information in patients' evaluation of health care and compliance decisions. <i>Southern Commun J.</i> , 56, 230-237.	Unable to locate this item.	N
Communication Style Measure	Y	Y	Norton, R.W. (1978) Foundation of a communication style construct. <i>Hum Commun Res</i> , 4, 99-112.	Norton, R.W. (1978) Foundation of a communication style construct. <i>Hum Commun Res</i> , 4, 99-112.	This is the same as the scale in row 58. It is not applicable for inclusion in the inventory as it measures individuals' preferences and self assessment of preferences, does not measure interaction. This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. <i>Patient Education and Counseling</i> , 35, 161-176.	N
Clinical Skills Assessment (assessing clinical skills of foreign medical graduates)	Y	Y		van Zanten, M., Boulet, J., & McKinley, D. (2007). Using Standardized Patients to Assess the Interpersonal Skills of Physicians: Six Years' Experience With a High-Stakes Certification Examination. <i>Health Communication</i> , 22(3), 195-205.	(Refers to measures but they are not included) Evaluates the use of standardized patients in the CSA assessment to determine if results are useful in identifying appropriate medical care skills. The scale has a couple of elements which evaluate communication skills so it is probably worth evaluating.	N

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Cancer Inventory of Problem Situations (CIPS): Medical Interaction Subscale	Y	Y		Glimelius, B., Nirgeford, G., Hoffman, K., Kvaes, G., Sjoden, P.O. (1995) Information to and communication with cancer patients: improvements and psychosocial correlates in a comprehensive care program for patients and their relatives. <i>Patient Education and Counseling</i> , 25, 171-182.	No Scale (This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. Patient Education and Counseling, 35, 161-176.)	N
Cancer Inventory of Problem Situations (CIPS): Medical Interaction Subscale	Y	Y		Schag, C.A.C., Heinrich, R.L., Ganz, P.A. (1983) Cancer inventory of problem situations: an instrument for assessing patients' rehabilitation needs. <i>Journal of Psychosocial Oncology</i> , 1 (4), 11-24.	This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. Patient Education and Counseling, 35, 161-176.	N
Cancer Inventory of Problem Situations (CIPS): Medical Interaction Subscale	Y	Y		Heinrich, R., Schag, C.C., Ganz, P.A. (1984) Living with cancer: The Cancer Inventory of Problem Situations. <i>Journal of Clinical Psychology</i> , 50 (4) 972-980.	This article was referenced in the Schag et al (1983 article. Article contains 3 items from the CIPS instrument.	N
Cancer Inventory of Problem Situations (CIPS): Medical Interaction Subscale	Y	Y		Makoul, G., Arntson, P. Schofield, T. (1995) Health promotion in primary care: physician-patient communication and decision making about prescription medications. <i>Social, Science and Medicine</i> , 41 (9) 1241-1254		N
Cancer Inventory of Problem Situations (CIPS): Medical Interaction Subscale	Y	N		Makoul, G. Perpetuating passivity: a study of physician-patient communication and decision making. Doctoral dissertation. Evanston, IL: Northwestern University, 1992.	Unable to locate this inventory in the referred document. This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. Patient Education and Counseling, 35, 161-176.	N

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Doctor-Patient Orientation Scale (DPOS)	Y	N		Krupat, E., Putnam, S., Yaeger, C. The fit between doctors and patients: can it be measured? 19th Annual Meeting of the Society of General Internal Medicine, Washington, D.C., 1996.	Unable to locate this inventory in the referred document. This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. Patient Education and Counseling, 35, 161-176.	N
Parents' Perceptions of Physicians' Communicative Behavior	Y	Y		Street, R.L.J. (1991) Physicians' communication and patients' evaluations of pediatric consultations. <i>Medical Care</i> , 29(11) 1146-1152	This instrument was referenced in Boon, H., Stewart, M. (1998) Patient-physician communication assessment instruments: 1986 to 1996 in review. Patient Education and Counseling, 35, 161-176. .	N
Parents' Perceptions of Physicians' Communicative Behavior	Y	Y		Street, R.L.J. (1992) Analyzing communication in medical consultations. Do behavioral measures correspond to patients' perceptions? <i>Medical Care</i> , 30 (11) 976-988.	behavioral measures- coding was conducted by listening to audio tape of the consultation Parent's satisfaction with children's care was assessed with a global measure on a scale of 1 to 10 to rate the satisfaction with your child's care.	N
	N	N		Srinivasan, M., Franks, P., Meredith, L.S., Fiscella, K., Epstein, R.M., Kravitz, R.L. (2006) Connoisseurs of care? Unannounced standardized patients' ratings of physicians. <i>Medical Care</i> , 44 (12) 1092-1098.		N
	N	N		Dolan Mullen, R., Dacey Allen, J., Glanz, K., Fernandez, M.E., Bowen, D.J., Pruitt, S.L., Glenn, B.A., Pignonoe, M. (2006) Measures used in studies of informed decision making about cancer screening a systematic review. <i>Annals of Behavioral Medicine</i> , 32 (3): 188-201.		N

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	N	N		Charles, C., Gafni, A., Whelan, T. (1999) Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. <i>Social Science and Medicine</i> , 49, 651-661.		N
	N	N		Whitney, S.N. McGuire, A.L., McCullough, L.B. (2003) A typology of shared decision making, informed consent, and simple consent. <i>Annals of Internal Medicine</i> , 140, 54-60.		N
Roter Method of Interaction Process Analysis (RIAS)	Y	N		Siminoff, L.A., Graham, G.C., Gordon, N.H. (2006) Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. <i>Patient Education and Counseling</i> , 62, 355-360.	This is a third party checklist of physician behaviors. It was not reviewed at this time.	N
	N	N		Krist, A.H., Woolf, S.H., Johnson, R.E., Kerns, J.W. (2007) Patient education on prostate cancer screening and involvement in decision making. <i>Annals of Family Medicine</i> , 5 (2) 112-119.		N
Physician Behavior Check List (PBCL)	Y	Y	Christina G. Blanchard, Mark S. Labreque, John C. Ruckdeschel, Edward B. Blanchard	Blanchard, C.G., Labreque, M.S., Ruckdeschel, J.C., Blanchard, E.B. (1988). Information and decision-making preferences of hospitalized adult cancer patients. <i>Social, Science & Medicine</i> , 27 (11) 1139-1145.	34 behaviors measuring in terms of their occurrence/nonoccurrence. Instrument not included in article; need to get this tool.	Y
Patient Satisfaction Questionnaire (PSQ)	Y	Y	PBCI developed for this particular study—Zanbelt, Smets, Oort, Godfried, de Haes	Zandbelt, L.C., Smets, E.M.A., Oort, F.J., Godfried, M.H., de Haes, H.C.J.M. (2007) Medical specialists' patient-centered communication and patient-reported outcomes (2007) <i>Medical Care</i> , 45 (4): 330-339.		N

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No name (Questionnaire Survey of Older People)	Y	Y		Arora, N.K., McHorney, C.A., (2000) Patient preferences for medical decision making: Who really wants to participate? <i>Medical Care</i> . 38 (3) 335-341	Need to get this tool.	N
Patient Perception of Patient-Centeredness (PPPC)	Y	N	Stewart, M., Brown, J.B., Donner A et al. (2000). The Impact of Patient-Centered Care on Outcomes. <i>The Journal of Family Practice</i> , 49(9):796-804.	Fiscella, K., Franks, P., Srinivasan, M., Kravitz, R.L., Epstein, R. (2007). Ratings of physician communication by real and standardized patients. <i>Annals of Family Medicine</i> , 5 (2) 151-158.	Article does not include the survey or references to the questions. Unable to locate this scale at the present time.	N
Modified Health Care Climate Questionnaire (HCCQ)	Y	Y	Original version of HCCQ by Williams, GC, McGregor HA, Zeldman A., Feedman, Z.R., Deci E.L.	Fiscella, K., Franks, P., Srinivasan, M., Kravitz, R.L., Epstein, R. (2007). Ratings of physician communication by real and standardized patients. <i>Annals of Family Medicine</i> , 5 (2) 151-158.	Found original version of HCCQ at http://www.psych.rochester.edu/SDT/measures/pashealth.php	N
Facilitation of Patient Involvement Scale	Y	Y	Martin, L., DiMatteo, R., Lepper, H.S.	Martin, L., DiMatteo, R., Lepper, H.S., (2001) Facilitation of patient involvement in care: development and validation of a scale. <i>Behavioral Medicine</i> , 27, 111-120.	9 item measure of the degree to which patients perceive that their physicians actively facilitate or encourage them to be involved in their own healthcare	N
CARES (Cancer Rehabilitation Evaluation System)- medical interaction subscale	Y	Y	CAC Schag and RL Heinrich	Collie, K., Wong, P., Tilston, J., Butler, L.D., Turner-Cobb, J., Kreshka, M.A., Parsons, R., Graddy, K., Cheasty, J.D., Koopman, C. (2005) Self-efficacy, coping, and difficulties interacting with health care professionals among women living with breast cancer in rural communities. <i>Psycho-Oncology</i> , 14, 901-912.	CARES was derived from the Cancer Inventory of Problem Situations by Heinrich et al.	Y

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Assessment of Patients' Experience of Cancer Care Study (currently under development)	Y	Y	National Cancer Institute and Northern California Cancer Center	National Cancer Institute and Northern California Cancer Center		N
Control Preferences Scale	Y	Y		Hawley, S.T., Lantz, P.M., Janz, N.K., Salem, B., Morrow, M., Schwartz, K., Liu, L., Katz, S.J. (2006) Factors associated with patient involvement in surgical treatment decision making for breast cancer. <i>Patient Education and Counseling</i> , 65, 387-395.		N
patient-surgeon communication variables	Y	Y		Hawley, S.T., Lantz, P.M., Janz, N.K., Salem, B., Morrow, M., Schwartz, K., Liu, L., Katz, S.J. (2006) Factors associated with patient involvement in surgical treatment decision making for breast cancer. <i>Patient Education and Counseling</i> , 65, 387-395.		N
Giving bad news	Y	Y		Back, A., L., Arnold, R.M., Baile, W.F., Fryer-Edwards, A.F., Alexander, S.C., Barley, G.E., Gooley, T.A., Tulsky, J.A. (2007) Efficacy of communication skills training for giving bad news and discussing transitions of palliative care. <i>Archives of Internal Medicine</i> , 167, 453-460.		N
Verbal Behavior Coding Guide	N	N		Source not found	(Have printed copy of instrument)	N

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Roter's Interaction Analysis System (RIAS)	Y	Y	D.L. Roter	Sandvik, M., Eide, H., Lind, M., Graugaard, P.K., Torper, J., Finset, A. (2002) Analyzing medical dialogues: strength and weakness of Roters' interaction analysis system (RIAS). <i>Patient Education and Counseling</i> , 46, 235-241.	(RIAS coding categories in Table 1 of article). This is a critique of the RIAS coding system rather than a review of the system itself. The article offers criticism of the coding system for problems in coding more complex communication and emotional exchanges that occur. The article does not provide statistics on the use of the coding system and does not contain a copy of the system.	N
Quality of Dying and Death (QODD) questionnaire	N	N	J. Randal Curtis, Donald L. Patrick, Ruth A. Engelberg, Kaye Norris, Charles Asp, Ira Byock	Curtis, J.R., Patrick, D.L., Engelberg, R.A., Norris, K., Asp, C., Byock, R. (2002) A measure of the quality of dying and death: Initial validation using after-death interviews with family members. <i>Journal of Pain and Symptom Management</i> , 24 (1)	(See appendix in article) Not deemed critical for initial review, so this instrument was skipped.	Y
Physician Belief Scale	N	N	Clark D. Ashworth, Penelope Williamson, Daniel Montano	Ashworth, C. D., Williamson, P., Montano, D. (1984) A scale to measure physician beliefs about psychosocial aspects of patient care. <i>Social, Science & Medicine</i> , 19, 1235-1238.	(Table 1 in article) Tool measures physicians beliefs, not eligible for inclusion in patient survey	Y
Patient-Centered behavior coding instrument (PBCI)	Y	Y	Zandbelt, Smets, Oort, de Haes	Zandbelt, L.C., Smets, E.M.A., Oort, F.J., de Haes, H.C.J.M (2005) Coding patient-centered behavior in the medical encounter. <i>Social Science and Medicine</i> , 61, 661-671.	(Table 1 and table 2 in article) The PBCI was developed to determine the occurrence of physician's facilitating and inhibiting behaviors. Validity was assessed by the Eurocommunication Scale (Mead & Bower, 200a)	N

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No name (study developed 8 written vignettes describing various degrees of control over treatment decisions)	N	N	vignettes developed by Degner & Aquino Russell	Degner, L.F., Aquino Russell, C. (1988) Preferences for treatment control among adults with cancer. <i>Research in Nursing and Health</i> , 11, 367-374.	(Table 2 in article) Other measures mentioned in article (although authors claim not designed specifically to elicit preferences for control over treatment decisions) The Krantz Health Opinion Survey (Krantz, Baum, & Wideman 1980), Desire for Control of Health Care Measure (Smith et al, 1984), & the Multidimensional Health Locus of Control Scale (Dickson, Dodd, Carrieri, & Levenson, 1985)	N
No name (questionnaire)	Y	Y	Walter F. Baile, Renato Lenzi, Patricia A. Parker, Rober Buckman and Lorenzo Cohen	Baile, W.f., Lenzi, R., Parker, P., Buckman, R., Cohen, L. (2002) Oncologists' attitudes toward practices in giving bad news: an exploratory study. <i>Journal of Clinical Oncology</i> , 20 (8) 2189-2196	(Table 1 and table 2 contain some items)	N
No name (Card sorts with two sets of 5 cards and the Symptom Distress Scale)	N	N	System Distress Scale developed by R. McCorkle and K. Young (reference in article)	Degner, L.F., Sloan, J.A. (1992) Decision making during serious illness: what role do patients really want to play? <i>Journal of Clinical Epidemiology</i> , 45 (9) 941-950.	(The statements for the card sort are in Figure 1) Not deemed critical for initial review, so this instrument was skipped.	Y
No name - (Outcome of a Workshop for Oncologists)	N	N	Walter F. Baile, Renato Lenzi, Andrzej P. Kudelka, Peter Maguire, Dennis Novack, Michael Goldstein, Eric G. Myers, Robert C. Bast	Baile, W. F., Lenzi, Renato, Kudelka, A. P., Maguire, P., Novack, D., Goldstein, M., Myers, E. G., Bast, R. C. (1997). Improving physician-patient communication in cancer care: outcome of a workshop for oncologists. <i>Journal of Cancer Education</i> , 12, 166-173.	(Tables of topics, schedule and outcomes of the workshop). Tool measures physician confidence in communication, not eligible for inclusion in patient survey. Not deemed critical for initial review, so this instrument was skipped.	Y

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Cancode	Y	Y	Dent, Brown, Dowsett, Tattersall, Butow	Dent, E., Brown, R., Dowsett, Tattersall, M., Butow, P. (2005) The Cancode interaction analysis system in the oncological setting: reliability and validity of video and audio tape coding. <i>Patient Education and Counseling</i> , 56, 35-44.	(Cancode structure in Table 1 of article). Third-party coding, not eligible for use as patient self-report.	N
Audiotapes analyzed using Roter Interaction Analysis System (RIAS) and 16-item satisfaction questionnaire	N	N		Paashe-Orlow, M., Roter, D. (2003) The communication patterns of internal medicine and family practice physicians. <i>Journal of the American Board of Family Practice</i> , 16 (6) 485-493.	(Categories in RIAS system in table 6)	N
	N	N		Coffman, J. (2007) Evaluating advocacy [PowerPoint Presentation] Research and Evaluation Conference: Robert Wood Johnson Foundation. http://www.rwjf.org/files/research/coffmanrwjfevaluation.pdf		N
Direct observation of visits followed by videotape-triggered stimulated recall sessions. Decision moments were coded for evidence of Shared Decision making	Y	Y		Saba, G.W., Wong, S.T., Schillinger, D., Fernandez, A., Somkin, C.P, Wilson, C.C., Grumbach, K. (2006) Shared decision making and the experience of partnership in primary care. <i>Annals of Family Medicine</i> , 4 (1) 54-62.		N
	N	N		Wilkinson, S. Chodak, G. (2003) Informed consent for prostate- specific antigen screening. <i>Urology</i> , 61, 2-4.		N

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UCLA/ RAND Prostate Cancer Index and the Groningen University questionnaire	N	N		Caffo, O., Amichetti, M. (1999) Evaluation of sexual life after orchidectomy followed by radiotherapy for early-stage seminoma of the testis. <i>BJU International</i> , 83, 462-468.	(Table 2 in article). Not deemed critical for initial review, so this instrument was skipped.	Y
Stimuli frame variables (symptom number and symptom bother calculated using a modified version of the symptom distress scale developed by McCorkle & Young, 1978)	N	N		Clayton, M., Mishel, M.H., Belyea, M. (2006) Testing a model of symptoms, communication, uncertainty, and well-being, in older breast cancer survivors. <i>Research in Nursing and Health</i> , 29, 18-39.	(Figure 1 in article shows the modified version of the scale)	N
Semantic Differential List	N	N	Silverfarb and Levine (?)	Silberfarb, P.M., Levine, P.M. (1980) Psychosocial aspects of Neoplastic Disease. <i>General Hospital Psychiatry</i> , 3, 192-197.	(Table 1 in article). Not deemed critical for initial review, so this instrument was skipped.	Y
Perceived Talk-Post-visit Instrument	N	N	Street et al.	Street, R.L., Voigt, B., Geyer, C., Manning, T., Swanson, G.P. (1995) Increasing patient involvement in choosing treatment for early breast cancer. <i>Cancer</i> , 76 (11) 2275-2285	Have instrument- unable to find actual source.	N
Control Over Decision measure	N	N		Source not found		N
Assessment of Care for Chronic Conditions	N	N		MacColl Institute for Healthcare Innovation, Group Health Cooperative 2004		N
APOS Quality Indicators	N	N	American Psychosocial Oncology Society			N

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	N	N		Charon, R., Greene, M.G., Adelman, R.D. (1994) Multi-dimensional interaction analysis: a collaborative approach to the study of medical discourse. <i>Social, Science and Medicine</i> , (39) 7, 955-965.	PDF file of the article is damaged. We will order a new copy of this article.	N
Words Emotionally Related to Dying (WERD) (adapted from Henbest and Stewart)	N	N		Barnett, M., McMichael, H. Journal of Cancer Care. 1992; 1: 145-149	(No article or instrument, so this instrument was skipped.)	Y
Threatening Medical Situations Inventory (van Zuuren and Hanewald)	N	N		van Zuuren, F.J., Hanewald, G.J.F.P. Gedragstherapi. 1993; 26: 33-48 [transl]	(No article or instrument, so this instrument was skipped.)	Y
Threatening Medical Situations Inventory (TMSI)	N	N	TMSO- developed by van Zuuren and Hanewald 1980)	Ong, L.M.L., Visser, M.R.M., Van Zuuren, F.J., Rietbroek, R.C., Lammes, F.B., De Haes, J.C.J.M. (1999) Cancer patients' coping styles and doctor-patient communication. <i>Psycho-Oncology</i> , 155-166	(No article or instrument, so this instrument was skipped.)	Y
The Support Team Assessment Schedule (STAS) and the Hebrew Rehabilitation Centre for the Aged Quality of Life (HRCA-QL)	N	N		Higginson, I.J., McCarthy, M. (1994) A comparison of two measures of quality of life: their sensitivity and validity for patients with advanced cancer. <i>Palliative Medicine</i> , 8, 282-290.	STAS—17 items, each scaled 0 to 4. HRCA-QL—5 items scaled 0 to 2. Not deemed critical for initial review, so this instrument was skipped.	Y
The Patient Satisfaction Scale and concept of Factored Homogeneous Item Dimension (FHID)	N	N		Ware, J.E., Snyder, M.K. (1975) Dimensions of patient attitudes regarding doctors and medical care services. <i>Medical Care</i> . 13 (8) 669-682.	(Sample items only- Table 1). Satisfaction scale not deemed critical for initial review, so this instrument was skipped.	Y

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The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTCQLQ-C30)	N	N	EORTCQLQ-C30 was developed by Aaronson et al, 1993	Hack, T., F., Degner, L.F., Watson, P., Sinha, L. (2006) Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. <i>Psycho-Oncology</i> , 15, 9-19.	A card sort technique (by Degner et al.) was also used in this study.	N
The Community Breast Health Project (CBHP) scale of communication barriers (12 item Likert scale), a two column survey (open-ended questionnaire with 3 questions), the Patient-Doctor Interaction Scale, and the Physician Satisfaction Scale (3 item Likert scale)	N	N		Sepucha, K.R., Belkora, J.K., Mutchnick, S., Esserman, L. (2002) Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. <i>Journal of Clinical Oncology</i> , 20 (11) 2695-2700.	(Example of the Two Column Survey in Table 1). Not deemed critical for initial review.	Y
The Beck Hopelessness Scale/Information Styles Questionnaire	N	N	Cassileth, B., Zupkis, R.V., Sutton-Smith, K., March, V.	Cassileth, B., Zupkis, R.V., Sutton-Smith, K., March, V. (1980) Information and participant preferences among cancer patients. <i>Annals of Internal Medicine</i> , 92, 832-83.	Cassileth Information Styles Questionnaire is mentioned, article states it can be obtained "by request". Not deemed critical for initial review.	Y
Support Team Assessment Schedule (STAS)	N	N		Higginson I.J., McCarthy M. Palliative Medicine 1993; 7: 219-228. Support Team Assessment Schedule	(No article or instrument). Not deemed critical for initial review.	Y

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Perceived Physician's Communication Style Scale	Y	Y	Perceived Physician's Communication Style developed for this study- by Takayama, Yamazaki, and Katsumata	Takayama, T., Yamazaki, Y., Katsumata, N., (2001) Relationship between outpatients' perceptions of physicians' communication styles and patients' anxiety levels in a Japanese oncology setting. <i>Social Science and Medicine</i> , 53, 1335-1350.		Y
State-Trait Anxiety Inventory (STAI) and two un-named instruments (see "notes column")	N	N	STAI- developed by CD Spielberger	Fogarty, L., Curbo, B., A., Wingard, McDonnell, K., Somerfield, M.R. (1999) Can 40 seconds of compassion reduce patient anxiety?. <i>Journal of Clinical Oncology</i> , 17 (1) 371-379	A total information recall score was obtained from 54 items asking what was recalled from videotapes. Also, physicians' characteristics were paired on a line (such as warm/ cold) Participant marked an X on the line closest to the word. Not deemed critical for initial review.	Y
Spielberger State-Anxiety Scale (to measure situational anxiety) and a 25 item Likert scale adapted from Roter and Korsch (used to measure patient satisfaction)	N	N	Spielberger State-Anxiety Scale developed by- DC Spielberger 1983	Leighl, N; Gattellari, M., Butow, P., Brown, R., Tattersall, M.H.N. (2001) Discussing adjuvant cancer therapy. <i>Journal of Clinical Oncology</i> , 19 (6) 1768-1778.	Not deemed critical for initial review.	Y
Spielberger State-Anxiety Form and the Information Styles Questionnaire.	Y	Y		Gattellari, M., Voigt, K.J., Butow, P.N., Tattersall, M.H.N. (2002) When the treatment goal is not cure: are cancer patients equipped to make informed decisions? <i>Journal of Clinical Oncology</i> , 20 (2) 503-513.	Table 1 shows the coding system used to code verbatim transcripts. Spielberger State-Anxiety Form not applicable.	Y

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Roter Method of Interaction Process Analysis (RIAS) and the German version of the POMS	N	N	RIAS was developed by D. Roter. The POMS was developed by the Educational and Industrial Testing Service	Mast, M.S., Kindlimann, A., Langewitz, W. (2005) Recipients' perspective on breaking bad news: how you put it really makes a difference. <i>Patient Education and Counseling</i> , 58, 244-251.	The RIAS was used to code the physician's communication in video clips. The German version of the POMS was used to measure 4 mood dimensions. Coding scheme used which was deemed critical for initial review.	Y
Physician Perspectives on Colorectal Cancer Screening" survey	N	N		Wolf, M.S., Baker, D.W., Makoul, G. (2006) Physician-patient communication about colorectal cancer screening. <i>Journal of General Internal Medicine</i> , 22 (11) 1493-1499.	PHYSICIAN SURVEY- which gauged physician perceptions regarding the standard of care for communication about colorectal cancer screening	N
Perception of the Interview Questionnaire (Delvaux)	N	N		Delvaux, N. Dissertation Universite Libre de Bruxelles; 1999	(No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y
Patient Satisfaction Questionnaire	N	N		Hays, R.D., et al. Scoring the medical outcomes study patient satisfaction questionnaire: PSQI-II. MOS memorandum. Santa Monica, CA: Rand Corporation, 1987 (unpublished),	(No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y
Patient satisfaction assessed using 22 items adapted from Roter and Korch	N	N		Dunn, S.M., Butow, P.N., Tattersall, H.N., Jones, Q.J., Sheldon, J.S., Taylor, J.J., Sumich, M.D. (1993) General information tapes inhibit recall of the cancer consultation. <i>Journal of Clinical Oncology</i> , 11 (11) 2279-2285.	Coding scheme used which was deemed critical for initial review.	Y

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Nursing Stress Scale (NSS), the Semantic Differential Attitude Questionnaire (SDAQ), the socio-demographic questionnaire, the Satisfaction with the Interview Assessment Questionnaire (SIAQ) and the EORTC QLQ-C30 evaluation	N	N		Delvaux, N. Razavi, D., Marchal, S., Bredart, A., Farvaques, C., Slachmuylder, J.L.(2004) Effects of a 105 hours psychological training program on attitudes, communication skills and occupational stress in oncology: a randomized study. <i>British Journal of Cancer</i> , 90, 106-114.	Coding scheme used which was deemed critical for initial review.	Y
No name (Survey)	N	N	Detmar, S.B., Aaronson, N.K., Wever, L.D.V., Muller, M., Schornagel, J.H.	Detmar, S.B., Aaronson, N.K., Wever, L.D.V., Muller, M., Schornagel, J.H. (2000) How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality-of-life issues. <i>Journal of Clinical Oncology</i> , 18 (18) 3295-3301.	Questionnaire categories were chosen because they were included in other measures: Functional Assessment of Cancer Therapy, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30, and the Short Form- 36 Health Survey (SF-36). There are no tools in this article so it was deemed not critical for initial review.	Y

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No name (Survey)	N	N	Rebecca G. Hagerty, Phyllis N. Butow, Peter A. Ellis, Elizabeth A. Lobb, Susan Pendlebury, Natasha Leighl, David Goldstein, Sing Kai Lo, and Martin H.N. Tattersall	Hagerty, R., Butow, P.N., Ellis, P., Lobb, E.A., Pendlebury, S., Leighl, S., Goldstein, Lo, S.K., Tattersall, M.H.N. (2004) Cancer Patient Preferences for Communication of Prognosis in the Metastatic Setting. <i>Journal of Clinical Oncology</i> . 22 (9) 1721-1730.	A survey was completed by participants, but not included in article. (No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y
No name (qualitative data collection by face-to-face interviews)	N	N		Butow, P.N., Dowsett, S., Hagerty, R., Tattersall, M.H.N. (2002) Communicating prognosis to patients with metastatic disease: what do they really want to know? <i>Support Care Cancer</i> , 10, 161-168.	Qualitative study (so, no tools with items), suggest we check if we have authors' publication (if any) from their quantitative study, CHECK if this article is a duplicate entry in this database. (No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y
No name (Patient self assessment of information and support for cancer care)	N	N		Weijmar Schultz, WCM, et al. <i>Journal of Psychosomatic Obstetrics and Gynecology</i> . 1986; 5: 119-127.	(No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y
No name (Patient satisfaction with physician and consultation)	N	N		Langewitz, W. <i>Psychother Psychosom Med Psychol</i> . 1995; 45: 351-357 [transl]	(No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y

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No name (Patient report of why the appointment was scheduled, what he/she intends to say or do in the appointment, and what thoughts or feelings he or she intends to share with the physician)	N	N		Argyris, C, (1993) Knowledge for action: A guide to overcoming barriers to organization change. San Francisco, CA: Jossey-Bass.	(No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y
No name (Patient report of why the appointment was scheduled, what he/she intends to say or do in the appointment, and what thoughts or feelings he or she intends to share with the physician)	N	N		Argyris, C, (ed). On Organizational Learning. Cambridge, UK: Blackwell; 1992.	(No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y
No name (measure of parents' satisfaction and perceptions of physicians' communication)	N	N		Street, R.L. (1992). Analyzing communication in medical consultations; Do behavioral measures correspond to patients' perceptions? <i>Medical Care</i> , 30 (11): 976-988.	behavioral measures- coding was conducted by listening to audio tape of the consultation Parent's satisfaction with children's care was assessed with a global measure on a scale of 1 to 10 to rate the satisfaction with your child's care.	N
No name (cross-sectional survey and card sorting)	N	N		Degner, L.F., Kristjanson, L. J., Bowman, D., Sloan, J. A., Carriere, K. C., O'Niel, J., Bilodeau, B., Watson, P., Mueller, B. (1997) Information needs and decisional preferences in women with breast cancer. <i>Journal of the American Medical Association</i> , 277, 1485-1492.		N

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No name (cross sectional survey adapted from the Cassileth Information Styles Questionnaire)	N	N		Lobb, E.A., Kenny, D.T., Butow, P.N., Tattersall, M.H.(2001) Women's preferences for discussion of prognosis in early breast cancer. <i>Health Expectations</i> , 4, 48-57.	(Some elements are listed) May be helpful in identifying constructs, but does not include a survey tool so it was deemed not critical for initial review.	Y
Medical Interaction Process System (MIPS)	N	N	Ford, Hall, Ratcliffe, Fallowfield	Ford, S., Hall, A., Ratcliffe, D., Fallowfield, L. (2000) The Medical Interaction Process System (MIPS): an instrument for analyzing interviews of oncologists and patients with cancer. <i>Social, Science and Medicine</i> , 50, 553-566.	(Content codes and modes are in Table 1 and 2 in article.) Instrument used for analyzing interviews of oncologists and patients with cancer-analysis of video and audio taped interactions	N
Measure of Patients' Preferences (MMP)	N	N	Patricia Parker, Walter F. Baile, Carl de Moor, Renato Lenzi, Andrzej P. Kudelka and Lorenzo Cohen	Parker, P., Baile, W.F., de Moor, C., Lenzi, R., Kudelka, A.,P., Cohen, L. (2001) Breaking bad news about cancer: patients' preferences for communication. <i>Journal of Clinical Oncology</i> , 19 (7) 2049-2056.	46 item measure was developed for this particular study. The Monitoring subscale of the Miller Behavioral Style Scale (MBSS) was used to demonstrate validity of the MMP. Deemed not critical for initial review.	Y
Japanese version of the Measures of Patient's Preferences (MPP-J)/ Japanese version of the Mental Adjustment Scale (MAC)/ Japanese version of the Hospital Anxiety and Depression Scale (HADS)	N	N	MAC was developed by Watson, M., Greer, S., Young, J, et al 2000 MPP developed by Parker, P.A., Baile, W.F., de Moor, C. et al 2001. HADS was developed by Zigmond, A.S. and Snaith R.P. (1983)	Fugjimon, M., Parker, P.A., Tatsuo, A., Sakano, Y., Baile, W.F., Uchitomi, Y (2007) Japanese cancer patients' communication style preference when receiving bad news. <i>Psycho-Oncology</i> , 16, 617-625	(Have measures from the original MPP- table 2 in article) Original MMP is a 46 item self rating scale developed to assess what items are important to American patients with cancer. The MAC is a 40-item measure developed to evaluate cancer patients' mental adjustment to their cancer after diagnosis. HADS is a scale of 14 items that assess anxiety and depressive symptoms.	N

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Interviews with patients that were recorded and transcribed. Analyzed according to Giorgi's step by step approach	N	N	Kirsti Kvale	Kvale, K., (2007) Do cancer patients always want to talk about difficult emotions? A qualitative study of cancer inpatients communication needs. <i>European Journal of Oncology Nursing</i> , 11, 320-327.		N
HRQL questionnaire & the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (aka QQLQ-C30)	N	N		Detmar, S.B., Muller, M.J., Schornagel, J.H. (2002) Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. <i>Journal of the American Medical Association</i> , 288 (23) 3027-3034.	Quality of life measure. Not deemed critical for initial review, so this instrument was skipped.	Y
Hospital Anxiety and Depression Scale and the Ways of Coping Checklist	N	N	Hospital Anxiety and Depression Scale- by A.S. Zigmond and RP Snaith The Ways of Coping Checklist- by P.P Vitaliano, J. Russo, JE Carr et al	Razavi, D., Merchaert, I., Marchal, S., Libert, Y., Conradt, S., Boniver, J., Etienne, A., Fontain, O., Janne, P., Klastersky, J., Reynaert, C., Scalliet, P., Slachmuylder, J., Delvaux, N. (2003) How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of post-training consolidation workshops. <i>Journal of Clinical Oncology</i> , 21 (16) 3141-3149.	Depressions and anxiety screening measures. Not deemed critical for initial review, so this instrument was skipped.	Y
Functional Assessment of Cancer Therapy (FACT)	N	N		http://www.facit.org/qview/qlist.aspx	Quality of life and health status measure. Not deemed critical for initial review, so this instrument was skipped.	N
Decisional Conflict Scale	N	N		O'Connor, A.M. Medical Decision Making. 1995; 15: 25-30.	(No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y

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Dartmouth COOP Functional Health Assessment charts/ WONCA	N	N		Sneeuw, K.C.A., Aaronson, N.K., Sprangers, M.A.G., Detmar, S.B., Wever, L.D.V., Schornagel, J.H. (1997) Value of caregiver ratings in evaluating the quality of life of patient with cancer. <i>Journal of Clinical Oncology</i> , 15 (3) 1206-1217.	Health status measures. Not deemed critical for initial review, so this instrument was skipped.	Y
Control Preferences Scale, Decisional Conflict Scale, Medical Outcomes Study Short Form 12, EuroQoL Health State Thermometer and a survey instrument regarding treatment choice developed by Daugherty et al.	N	N		Meropol, N.J., Weinfurt, K.P., Burnett, C.B., Balshem, A., Benson, A.B., Castel, L., Corbett, S., Diefenbach, M.D., Gaskin, D., Li, Y., Manne, S., Marshall, J., Rowland, J.H., Slater, E., Sulmasy, D.P., Van Echo, D., Washington, S., Shulman, K.A. (2003) Perceptions of patients and physicians regarding phase 1 cancer clinical trials: implications for physician-patient communication. <i>Journal of Clinical Oncology</i> , 13, 2589-2596.	The questionnaire consisted of 121 items. Instrument not included in article; need to get this tool.	N
Control Preferences Scale (CPS)	N	N	Lesley F. Degner, Jeff A. Sloan, Peri Venkatesh	Degner, L.F., Sloan, J. A., Venkatesh, P. (1997). The Control Preferences Scale. <i>Canadian Journal of Nursing Research</i> , 29, 21-43.		N
Community Breast Health Project Scale of Communication Barriers	N	N		Brainstorming Sessions Summary Report. Palo Alto, CA, Community Breast Health Project; 1994 (www-med.stanford.edu/CBHP/Brainstormin.html)	(No article or instrument provided in this reference so it was deemed not critical for initial review.)	Y

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Combination of new and previously validated instruments were used (SF-12 Health Survey and Ende's autonomy preference index) to develop a self-administered questionnaire	N	N	Shinji Matsumura, Seiji Bito, Honghu Liu, Katharine Kahn, Shunichi Fukuhara, Marjorie Kagawa-Singer, Neil Wenger	Matsumura, S., Bito, S., Liu, H., Kahn, K., Fukuhara, S., Kagawa-Singer, M., Wenger, N. (2002) Acculturation of attitudes toward end-of-life care: a cross-cultural survey of Japanese Americans and Japanese. <i>Journal of General Internal Medicine</i> , 17, 531-539.	Quality of life and health status measure. Not deemed critical for initial review, so this instrument was skipped.	Y
Cancer Rehabilitation Evaluation System-Short Form (CARES-SF)	N	N		Coscarelli Schag, C.A., Ganz, P.A., Heinrich, R.L., (1991) Cancer Rehabilitation Evaluation System- Short Form (CARES-SF) A cancer specific rehabilitation and quality of life instrument. <i>Cancer</i> , 68, 1406-1413.	This short form was developed from CARES	N
Cancer Consultation Preparation package (CCPP)	N	N	Phyllis Butow, Rhonda Devine, Michael Boyer, Susan Pendlebury, Michael Jackson, and Martin H.N. Tattersall A	Butow, P., Devine, R., Boyer, M., Pendlebury, S., Jackson, M., Tattersall, M.H.N. (2004). Cancer Consultation Preparation Package: Changing patients but not physicians is not enough. <i>Journal of Clinical Oncology</i> , 22 (21) 4401-4409.	Focused on measuring physician communication behavior. Not deemed critical for initial review.	Y
?	N	N		Kidd, J., Marteau, T.M., Robinson, S., Ukoumunne, O.C., Tydeman, C. (2004) Promoting patient participation in consultations: a randomized controlled trial to evaluate the effectiveness of three patient-focused interventions. <i>Patient Education and Counseling</i> , 52, 107-112	Not deemed critical for initial review.	Y

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(Adaptation of the) Physician Psychosocial Belief (PPSB) questionnaire	N	N	CD Ashworth, P. Williamson, D. Montano	Jenkins, V., Fallowfield, L. (2002) Can communication skills training alter physicians' beliefs and behavior in clinics? <i>Journal of Clinical Oncology</i> , 20 (3) 765-769.	Physician belief measure. Not deemed critical for initial review.	Y
Self management scale (not formal name)	Y	Y		Heisler, M., Bouknight, R.R., Hayward, R.A., Smith, D.M., Kerr, E.A. (2002) The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. <i>Journal of General Internal Medicine</i> , 17, 243-252.		N
Quality of life in colorectal cancer	Y	Y		Ayanian, J.Z., Zaslavsky, A.M., Guadagnoli, E., Fuchs, C.S., Yost, K. J., Creech, C.M., Cress, R.D., O'Connor, L.C., West, D.W., Wright, W.E. (2005) Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language, <i>Journal of Clinical Oncology</i> , 23 (27) 657-6586.		N
Patient's Perception of Physicians	Y	Y		Street, Medical Care November 1991 - Volume 29 - Issue 11 - pp 1146-1152		N
EORTC Patient Satisfaction Scale	Y	Y		Bredart, A., Bottomley, A., Blazeby, J.M., Conroy, T., Coens, C., D'Haese, S., Chie, W-C., Hammerlid, E., Arraras, J.I., Efficace, F., Rodary, C., Schraub, S., Costantini, M., Costantini, A., Joly, F., Sezer, O., Razavi, D., Mehrlitz, M., Bielska-Lasota, M., Aaronson, N.K., On behalf of the European Organisation for Research and Treatment of Cancer Quality of Life Group and Quality of Life Unit. (2005) An international prospective study of the EORTC cancer in-patient satisfaction with care measure (EORTC In-PATSAT32) <i>European Journal of Cancer</i> , 41, 2120-2131.		N

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Medical Communication Competence Scale	Y	Y		Cegala, D.J., Coleman, M.T., Warisse Turner, J. (1998) The development and partial assessment of the Medical Communication Competence Scale, <i>Health Communication</i> , 10 (3), 261-288.		N
The Consultation and Relational Empathy (CARE) measure	Y	Y		Mercer, S.W., Maxwell, M., Heaney, D., Wat, G.C.M. (2004) The consultation and relational empathy (CARE) measure: development and preliminary validation and reliability of an empathy-based consultation process measure. <i>Family Practice</i> . 21 (6) 699-705)		N
CAHPS Clinician and Group Survey 1.0- Adult Primary Care Questionnaire (UPDATED OCTOBER 2009)	Y	Y				N
various measures listed in article	Y	Y	various	Arora, N. K. (2003) Interacting with cancer patients: the significance of physicians' communication behavior. <i>Social Science and Medicine</i> . 57, 791-806.	This article reviews a variety of measures used to assess physician communication behavior. These include both self-report, patient report, and communication coding schemes. There are now scales provided in the article but a number that we will pursue based on their description the paper.	N
Patient Reactions Assessment	Y	Y		Galasi, J.P., Schanberg, R., Ware, W.B. (1992) The patient reactions assessment: A brief measure of the quality of the patient-provider relationship. <i>Psychological Assessment</i> , 4, 346-351.		N

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The Princess Margaret Hospital Satisfaction Questionnaire	Y	Y		Loblaw, D.A., Bezjak, A. (1999) Development and testing of a visit-specific patient satisfaction questionnaire: The Princess Margaret Hospital Satisfaction with Doctor Questionnaire. <i>Journal of Clinical Oncology</i> , 17, 1931.		N
Cancer Diagnostic Interview Scale (CDIS)	Y	Y		Roberts, C. S., Cox, C.E., Reintgen, D.S., Baile, W.F., Gibertini, M. (1994) Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. <i>Cancer</i> , 714 (1 Suppl): 336-341.		N
OPPQNCS Long Form (SAMPLE)	Y	Y	Laurel E. Radwin (Massachusetts General Hospital-The Institute for Patient Care)	http://www2.massgeneral.org/pccs/The_Institute_for_Patient_Care/YM/Tools/OPPQNCS/OPPQNCSLong.pdf		N
Assessment of Doctor-Elderly Patient Transaction (ADEPT)	Y	Y		Teresi, J.A., Ramirez, M., Ocepek-Welikson, Cook, M.A. (2005) The development and psychometric Analyses of ADEPT: an instrument for assessing the interactions between doctors and their elderly patients. <i>Annals of Behavioral Medicine</i> , 30 (3) 225-242.		N
SCOPE	Y	Y		James A. Tulskey- Duke University. IRB# 4510-06-2R3ER		N
Dyadic OPTION scale	Y	Y		Melbourne, E., Sinclair, K., Durand, M.A., Legare, F., Elwyn, G. (2010) Developing a dyadic OPTION scale to measure perceptions of shared decision making. <i>Patient Education and Counseling</i> , 78, 177-183.		N

Effective Health Care Program Research Report Number 39

Name of the instrument (Name of instrument, scale or questionnaire, if it is known)	To be reviewed (Y/N) (Instrument to be reviewed in the inventory process)	Instrument Reviewed (Y/N) (Indicates review is complete)	Authors (This column is used to acknowledge scale or measure authors where they are known)	Citation (This column is used to indicate the citation of the article discussing the scale or presenting the findings related to PCC)	Notes (This column is used to provide any notes on the articles that may be helpful in evaluating the PCC scales and articles)	Included in the PCC Monograph (Y/N)
OPTION scale	Y	Y		Elwyn, G., Wensing, M., Hood, K., Atwell, C., Grol, R. (2003) Shared decision making: developing the OPTION scale for measuring patient involvement. <i>Qual Saf Health Care</i> , 12, 93-99.		N
Article compares 3 coding systems (DSAT, DAS-O, OPTION) mapped against the Makhoul competencies of SDM	Y	Y		Butow, P., Juraskova, I., Chang, S., Lopez, A.L., Brown, R., Bernhard, J. (2010) Shared decision making coding systems: How do they compare in the oncology context? <i>Patient Education and Counseling</i> , 78, 261-268.		N
CanCORS Brief Patient Survey (MD) version 7.0 (3/17/2004)	Y	Y		Ayanian, J.Z., Chrischilles, E.A., Fletcher, R.H., Fouad, M.N., Harrington, D.P., Kahn, K.L., Kiefe, C.I., Lipscomb, J., Malin, J.L., Potosky, A., L., Provenzale, D.T., Sandler, R.S., van Ryn, M., Wallace, R.B., Weeks, J.C., West, D.W. Understanding cancer treatment and outcomes: the Cancer Care Outcomes Research and Surveillance Consortium. <i>Journal of Clinical Oncology</i> 2004; 15:2992-2996.		N
CanCORS Survivorship Follow-up Survey (8/31/2004)	Y	Y		Ayanian, J.Z., Chrischilles, E.A., Fletcher, R.H., Fouad, M.N., Harrington, D.P., Kahn, K.L., Kiefe, C.I., Lipscomb, J., Malin, J.L., Potosky, A., L., Provenzale, D.T., Sandler, R.S., van Ryn, M., Wallace, R.B., Weeks, J.C., West, D.W. Understanding cancer treatment and outcomes: the Cancer Care Outcomes Research and Surveillance Consortium. <i>Journal of Clinical Oncology</i> 2004; 15:2992-2996.		N

Appendix H. Objective 2: PCC Item Inventory

This appendix is in a separate Excel file at www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=1429.

Appendix I. Objective 2: Final PCC Functions and Domains

PCC Functions and Domains: Final (Revised June 21, 2010)

EXCHANGING INFORMATION

- **Exploring Knowledge, Beliefs, and Information Needs and Preferences**
 - Exploring, identifying, and expressing information preferences and needs (e.g., preferences for type/level of information, including for learning “bad news”)
 - Asking questions, expressing concerns, seeking information
 - Perceptions and judgments about whether provider encourages questions, information seeking
 - Exploring, identifying, and expressing knowledge and beliefs (e.g., related to causality, prognosis, treatment options, side effects, recurrence, self-care) and reasons for knowledge and beliefs
 - Discussing misinformation (e.g., sources, reasons for believing)
 - Perceptions and judgments about whether provider addresses and explains any misinformation
 - Acknowledging and discussing any differences of beliefs and opinions
- **Sharing Information**
 - Sharing information about cancer experience (“cancer story”), including experiences with diagnosis, cancer care, effects on quality of life, and barriers/facilitators for care
 - Perceptions and judgments about whether provider values learning patient’s “cancer story”
 - Perceptions and judgments about whether provider shares information in a way they can understand
 - Perceptions and judgments about whether provider shares information consistent with their preferences (e.g., for type and level of information, including preferences for learning “bad news”)
 - Perceptions and judgments about whether provider anticipates their information needs and provides relevant, useful information proactively
 - Perceptions and judgments about whether provider checked that information needs were met
- **Providing Informational Resources and Helping Patients/Family Members Evaluate and Utilize Resources**
 - Discussing sources used for cancer information (e.g., whether sources trustworthy)
 - Exploring and identifying need for informational resources and identifying suitable resources
 - Perceptions and judgments about assistance provided to evaluate information

- Perceptions and judgments about information resources provided (e.g., whether relevant, easy to use, met their needs)
- **Facilitating Assimilation, Understanding, and Recall of Information**
 - Perceptions and judgments about whether information provided was appropriate for them (e.g., in terms of how easy to read, relevant to their situation)
 - Perceptions and judgments about whether provider shared information in a way that made it easy to understand and recall (e.g., used everyday language, graphics, visual aids, repetition, summarization, explanation of medical terms, writing down information).
 - Whether provider suggested using methods to enhance recall (e.g., audio-recording, taking notes, bring family member or care giver to appointment)
 - Perceptions and judgments about whether provider checked for understanding.

FOSTERING HEALING RELATIONSHIPS

- **Discussion About Roles and Responsibilities**
 - Discussion of expectations and preferences related to roles and responsibilities (e.g., roles in making decisions; role of family members and other caregivers)
 - Negotiation, clarification, confirmation of roles and responsibilities
 - Discussion of shared goals for cancer care
- **Honesty, Openness, Disclosure**
 - Perceptions and judgments about whether provider encourages disclosure
 - Disclosure, sharing complete and honest information (e.g., about health behaviors, compliance, barriers to compliance, other health care received)
 - Perceptions and judgments about providers' disclosure consistent with patient preferences
 - Perceptions and judgments about provider's trustworthiness in terms of honesty
 - Perceptions and judgments about provider's honesty about any errors, misinformation, or misunderstandings
 - Perceptions and judgments about provider's trustworthiness in terms of ensuring confidentiality
- **Trust in Clinician's Technical Competence, Skills, and Knowledge**
 - Perceptions and judgments about provider's trustworthiness in terms of technical competence, skills, knowledge
 - Perceptions and judgments about provider's ability to get things done in the health care system
- **Expression of Caring and Commitment**
 - Perceptions and judgments about provider's commitment to their best interests
 - Perceptions and judgments about provider's commitment to patient's ongoing care (i.e. non-abandonment)

- Perceptions and judgments about provider's demonstration of caring (verbal and non-verbal)
- **Building Rapport and Connection**
 - Perceptions and judgments about whether provider knows and cares about them as an individual and as a "whole person" (not just as a patient)

MANAGING UNCERTAINTY

- **Constructing , Defining, and Understanding Uncertainty**
 - Exploring and identifying areas of uncertainty
 - Reducible vs. irreducible uncertainty
 - Distressing vs. non-distressing uncertainty
 - Potential impact and importance of uncertainty
 - Context for uncertainty (known vs. unknown)
 - Inquiring about unstated areas of uncertainty (provider)
 - Introducing uncertainty into situations where patient assumes certainty (provider)
 - Acknowledging uncertainty
 - Clarifying sources/reasons for uncertainty (e.g., lack of information, conflicting information, validity of evidence, etc.)
 - Expressing (and confirming) understanding of sources/reasons for uncertainty
 - Discussing conflicting advice from different sources (provider)
- **Using Emotion-focused Management Strategies (affective)**
 - Accepting irreducible uncertainty
 - Denying uncertainty/Choosing not to deal with uncertainty
 - Exploring, identifying, and expressing emotions that accompany uncertainty (e.g., anxiety, frustration)
 - Perceptions and judgments about provider's response to emotions associated with uncertainty
- **Using Problem-focused Management Strategies (behavioral)**
 - Exploring and identifying preferences for dealing with uncertainty
 - Customizing approach to meet patient needs (provider)
 - Discussing and formulating a plan for dealing with uncertainty (i.e., decision tree, contingency plan)
 - Perceptions and judgments about plan for dealing with uncertainty
 - Identifying information needs related to uncertainty; Seeking further information and resources (e.g., educational materials, Internet sites)
 - Perceptions and judgments about provider's response to information seeking

RECOGNIZING AND RESPONDING TO EMOTIONS

- **Expressing , Exploring, and Identifying Emotions**
 - Perceptions and judgments about whether provider accepts and encourages emotional expression
 - Exploring and identifying emotions
 - Perceptions and judgments about whether provider understands their emotions
 - Asking and answering questions to assess depression, anxiety, other psychological conditions
- **Acknowledgement and Validation Emotions**
 - Perceptions and judgments about whether provider acknowledges and validates emotions
- **Expression of Empathy, Sympathy, and Reassurance**
 - Perceptions and judgments about whether provider is empathetic
 - Perceptions and judgments about whether provider is sympathetic
 - Expressing, identifying, clarifying need for reassurance (e.g., what are specific concerns about which they need reassurance?)
 - Perceptions and judgments about whether provider is reassuring (e.g., reassurance about health, as appropriate; about relationship and commitment to patient's care and best interests)
- **Providing Tangible Help in Dealing with Emotions**
 - Discussion and identification of tangible help for dealing with emotions and emotional adjustment (e.g., counseling)
 - Medication prescriptions and/or referrals to support groups, counseling, therapy, and other assistance as appropriate
 - Development an action plan to get the help they need to deal with emotions and emotional adjustment
 - Perceptions and judgments about tangible help in dealing with emotions (e.g., whether resources and referrals are useful and relevant)

ENABLING SELF-MANAGEMENT & PATIENT NAVIGATION

- **Assessing, Sharing, and Advising**
 - Discussion of areas in which patients is interested in/motivated to change behavior,, barriers/concerns they have, confidence in undertaking the change, and their resources for doing so.
 - Discussion of areas in which help is needed for self-management
 - Discussion of patient's needs and desires (medical, social, financial, psychological including depression status) relevant to self-management.
 - Perceptions and judgments about whether provider understands and addresses their information and other needs relevant to self-management

- Sharing what is important to the patient including values and preferences for self-care and surveillance and health habits
- Sharing impact that condition(s) or changes in condition have on patient's life
- Bringing problems about condition or care to the provider's attention
- Seeking information needed to collaboratively set goals or develop a plan with providers
- Perceptions and judgments about whether provided helped to support patient autonomy
- Perceptions and judgments about whether provide taught them what they "can do"
- Perceptions and judgments about whether provider shared information appropriate for setting goals and developing a plan
- **Prioritizing , Planning, and Preparing**
 - Perceptions and judgments about whether provider helps them with tracking and monitoring condition and changes in condition
 - Discussing and making decisions collaboratively about goals and plans
 - Discussion to ensure understanding of the plan (specific steps, timeframe, role of patient, family and provider)
 - Perceptions and judgments about whether provider confirmed understanding of the goal and plans
 - Learning and practicing self-care skills (e.g., symptom management, administering medications, adhering to schedule, dealing with stress, etc.); discussing challenges
 - Perceptions and judgments about provider's teaching of self-care skills and addressing challenges
 - Practicing techniques to aid recall and understanding of information, instructions and skills
 - Perceptions and judgments about tools and resources provided to support self-management
 - Perceptions and judgments about provider's follow-up with patient about implementation of self-management plan (e.g., success, failures, challenges)
 - Perceptions and judgments about provider's help in problem solving to facilitate self-management (e.g. addressing barriers, suggesting resolutions)
- **Arranging and Following-up**
 - Seeking assistance in communicating with other members of the cancer care team
 - Perceptions and judgments about whether provider facilitates communication with others on cancer care team
 - Perceptions and judgments about the provider linking them to outside resources (e.g. in community or healthcare system) and following up with patient about experience with these linkages
 - Discussion about the need for mid-course corrections to plan
 - Sharing information about what is working well, what is not, and new preferences/values based on experience

- **Patient Navigation**

- Sharing information related to patient navigation (e.g., information about types of assistance available)
- Addressing barriers to care
 - discussion of barriers to care including financial (e.g. insurance, welfare, disability)
 - perceptions and judgments about provider's assistance to address barriers to care (e.g., linking patient to support, services)
 - Discussion of cultural and language barriers to care
 - Perceptions and judgment about how provider addresses cultural and language barriers to care
- Overcoming health systems barriers
 - Perceptions and judgments about how provider addresses health care systems barriers (e.g. facilitating appointments, follow-up, referrals)
 - Perceptions and judgments about how provider facilitates coordination of care

MAKING DECISIONS

- **Communication about Decisional Needs, Decision Support, and Decision Process**

- Exploring, identifying, and expressing preferences for level of involvement (and family member/caregiver's level of involvement) in decision-making process (and who takes responsibility for choices)
- Discussion of expectations for communication related to decision making (e.g., mode of communication, level of detail)
- Seeking and discussing information to support decision making (e.g., about options, risks, benefits, probabilities)
- Sharing information to support decision making (e.g., values, preferences, experiences)
- Exploring, identifying, and expressing other support needed for decision making (e.g., psychological support, decision aids, coach, navigator)
- Perceptions and judgments about whether provider shared information for decision-making

- **Preparation for the Decision and Deliberation**

- Perceptions and judgments about whether provider let them know when there were choices and decisions to be made
- Asking questions and discussing to confirm understanding of different options and their pros/cons
- Perceptions and judgments about whether provider checked to ensure patient understanding of the choices
- Clarifying and expressing opinions, values, and preferences related to different options
- Perceptions and judgments about whether provider understands patient's preferences and values related to different options
- Exploring, identifying, and expressing certainty (or uncertainty) about options and choices and direction one is leaning in and why
- Perceptions and judgments about whether provider addressed areas of uncertainty

- Discussing health care provider's recommendation and opinions (including uncertainties)
- Perceptions and judgments about provider's discussion about recommendation (e.g. explanation of reasons for recommendation, whether explained any medical guidelines, evidence)
- Exploring and discussing reactions to recommendation, any differences of opinion, decisional conflict/ambivalence anxiety, doubts, questions
- Perceptions and judgments about deliberation (e.g., whether helpful in making decision)
- **Making and Implementing a Decision and Action Plan**
 - Provider asks about patient's choice (or if would prefer family member, other caregiver, or provider to make choice)
 - Exploring and discussing implications of choice and next steps
 - Perceptions and judgments about discussion of choice (e.g. whether provider confirmed patient's understanding of choice and implications of choice).
 - Discussion of implementation of choice (e.g. how to address potential barriers)
- **Assessing Decision Quality and Reflecting on Choice**
 - Sharing experience implementing plan (e.g., ease/difficulty of implementing, barriers)
 - Discussing outcomes of decision (e.g., effects on quality of life)
 - Expressing satisfaction with/other perceptions about choice (e.g., whether made "right decision," regrets, blame)
 - Expressing satisfaction with/other perceptions about participation in decision making (e.g., whether as involved as wanted to be)
 - Discussing whether/how to revise/build on prior choice/plan

CROSSCUTTING DOMAINS

- **Time for Communication**
 - Sufficient time for communication
 - Good use of time
- **Setting for Communication**
 - Privacy
 - Lack of interruptions
 - Quiet
- **Communication about Cancer Care Team**
 - Explains and clarifies roles and responsibilities of different members of cancer care team in patient's care
 - Communication about coordination among clinicians
- **Basic interpersonal communication skills**
 - Not interrupting
 - Paying full attention
 - Listening attentively
 - Showing respect and courtesy

Appendix J. Objective 2: Cognitive Testing Instrument

Exchanging Information

Instructions: The next few questions ask about the information that you and your main doctor might discuss.

Your Understanding and Preferences

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent do you and your doctor discuss...								
1. what you already know and understand about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
2. what you already know and understand about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
3. your concerns and questions about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
4. your concerns and questions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
5. how much information you would like to have about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
6. how much information you would like to have about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
7. any differences of opinions or beliefs about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
8. any differences of opinions or beliefs about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Your Opinions and Questions

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
9.	show interest in your cancer experience?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
10.	ask you to share your cancer experience with him or her?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
11.	make you feel comfortable asking questions or talking about your concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
12.	make it easy for you to share personal or sensitive information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
13.	listen carefully to what you have to say about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
14.	listen carefully to what you have to say about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
15.	check to be sure he or she understands what you say?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Information Given by Your Doctor

		Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
How often does your doctor...									
16.	give you helpful information, even when you don't ask for it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
17.	suggest information that is helpful to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
18.	make sure you have the information you need and want?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
19.	show you pictures, graphs, or other materials to help you understand important information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
20.	give you brochures, written information, or other materials to help you remember important information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
21.	give you materials (e.g., brochures, DVDs or videos, web sites) that are helpful to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
22.	tell you where you can get other information you need (e.g. from websites, organizations)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
23.	explain things in a way that is clear and easy to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
24.	explain information in different ways to help you understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
25.	help you understand the information you need to know about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
26.	help you understand the information you need to know about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
27.	make sure you understand important information about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
28.	make sure you understand important information about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
29.	check to be sure your questions are answered?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
30.	let you know if you misunderstood any information about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>
31.	let you know if you misunderstood any information about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
32.	check to see what kinds of information you would like to have about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
33.	check to see what kinds of information you would like to have about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
34.	understand what kinds of materials (e.g., brochures, DVDs or videos, web sites) might be helpful for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
35.	discuss with you information that you get from other places (e.g., information you find on the Internet)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Sharing Difficult News

Sometimes, doctors have to share difficult (or “bad”) news with cancer patients.

36. Has your doctor has ever had to share any bad news with you about your cancer care?

☐ Yes → Go to 37

☐ No → Stop

☐ Don't know → Stop

☐ Does Not Apply → Stop

37. Has your doctor asked how you would like to learn about any bad news?

☐ Yes

☐ No

☐ Does Not Apply

38. Does your doctor share bad news with you in the way that you like?

☐ Yes

☐ No

☐ Does Not Apply

		Excellent	Very Good	Good	Fair	Poor	Does Not Apply	
							Don't Know	
How well does your doctor share bad news...								
39.	in the way that is right for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
40.	in a way that is sensitive to your needs and feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>

Fostering Healing Relationships

The next few questions ask about things that your doctor may have done to build a good relationship with you. Specifically, the questions ask if you are treated as an individual, are given good explanations about roles/responsibilities for your care, and can speak openly / honestly with your doctor.

Care and Concern

		Very Much	A Fair Amount	Somewhat	A Little	Not at All	Don't Know		Does Not Apply
To what extent does your doctor...									
1.	show that he or she cares about you as an individual person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
2.	show real interest in you as an individual person, not just in your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
3.	try to get to know you as an individual person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
4.	show real concern for you and your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
5.	remember details about you between visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
6.	treat you as an individual?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
7.	treat you as a person, not just another patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
8.	show that he or she cares about you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
9.	show that he or she cares about your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
10.	consider what is best for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
11.	show commitment to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
12.	show that he or she cares about your health needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
13.	show interest in your background and culture?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Your Doctor's Role and Your Role

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Does Not Apply	Don't Know
To what extent do you and your doctor discuss...									
14.	how you will work together as a team during your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
15.	his or her role in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
16.	how you would like to be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
17.	how you could be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
18.	his or her desire for you to be actively involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
19.	how you would like your family (or caregivers) to be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
20.	how your family (or caregivers) could be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Communicating With Your Doctor

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Does Not Apply	Don't Know
To what extent do you and your doctor...									
21.	discuss the importance of open and honest communication?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
22.	have open and honest communication, including differences of opinion?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
23.	feel comfortable sharing information openly and honestly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
24.	share information in a way that you prefer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
25.	share complete and honest information with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
26.	share information with your family (or caregiver) in a way that you prefer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
27.	share complete and honest information with your family (or caregiver)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent does your doctor talk in a way that makes you...								
28.	feel he or she is well informed about your type of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29.	feel he or she is up-to-date with the latest treatment choices for your type of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30.	feel confident in his or her ability to meet your cancer care needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31.	trust in his or her ability to provide you with the care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32.	trust him or her with personal or sensitive information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Does Not Apply	Don't Know	Poor	Fair	Good	Very Good	Excellent
How well does your doctor seem to communicate...								
33.	with other healthcare providers who help take care of you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.	with other healthcare providers to make sure that you get the care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Dealing with Mistakes

35. As far as you are aware, have there been any medical mistakes or errors in your cancer care?

- ☐ Yes → Go to 36A
- ☐ No → Skip to next section

- ☐ Don't Know → Skip to next section
- ☐ Does Not Apply → Skip to next section

35A. Did your doctor discuss the medical mistake or error with you?

- ☐ Yes → Continue
- ☐ No → Stop

- ☐ Does Not Apply → Stop

35B. How well did your doctor discuss the medical mistake or error with you?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

- ☐ Does Not Apply

Managing Uncertainty

Introductions: During medical care, there may be situations where there is not a clear answer or where doctors and patients don't know the answer to an important question. For example, experts sometimes disagree about which treatment is best, or doctors cannot be sure which side effects will occur during treatment. These types of situations can cause uncertainty for patients.

The next section asks about the uncertainties you have experienced in your care. It also asks how you and your main doctor have discussed or dealt with these uncertainties.

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1. What types of uncertainties have you experienced in the course of your cancer care? (Check all that apply.)

Types of uncertainties...

- | | |
|--|--------------------------|
| a. What is my diagnosis? | <input type="checkbox"/> |
| b. What is my prognosis? | <input type="checkbox"/> |
| c. What are the treatment choices? | <input type="checkbox"/> |
| d. Which treatment will be best for me? | <input type="checkbox"/> |
| e. What are the chances of my cancer coming back? | <input type="checkbox"/> |
| f. What kinds of side effects I will have from treatment? | <input type="checkbox"/> |
| g. How I will cope with side effects of treatment? | <input type="checkbox"/> |
| h. Where should I go for treatment? | <input type="checkbox"/> |
| i. How do I choose a doctor? | <input type="checkbox"/> |
| j. What do different doctors and health care providers do? | <input type="checkbox"/> |
| k. Will health insurance cover my treatment? | <input type="checkbox"/> |
| l. Will I be able to work during (or after) treatment? | <input type="checkbox"/> |
| m. Can I carry out my family responsibilities during (or after) treatment? | <input type="checkbox"/> |
| n. Can I continue with my usual activities during (or after) treatment? | <input type="checkbox"/> |
| o. How will cancer affect my everyday life? | <input type="checkbox"/> |
| p. How should I tell my family or friends about my cancer? | <input type="checkbox"/> |
| q. What are my rights as a patient? | <input type="checkbox"/> |
| r. What is my role in making decisions about my care? | <input type="checkbox"/> |
| s. What is my family's role in making decisions about my care? | <input type="checkbox"/> |
| t. Other issues or situations | <input type="checkbox"/> |

Please specify: _____

2. Has your doctor ever told you that sometimes there are uncertainties in cancer care? ☐ Yes ☐ No

	Always	Often	Sometimes	Rarely	Never	Don't Know	Does Not Apply
How often do you and your doctor...							
3. discuss uncertainties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. discuss your questions about the uncertainties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Reasons for Uncertainty

		Excellent	Very Good	Good	Fair	Poor	Don't Know	Does Not Apply
How well does your doctor...								
5.	identify possible sources of uncertainty in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6.	explain the reasons for uncertainty in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.	share the information you want about the uncertainties that affect your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8.	help you make sense of the uncertainties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.	explain uncertainties caused by experts not having enough information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.	explain the uncertainties that experts disagree about?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11.	help you understand <u>why</u> experts have different opinions about your type of cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12.	respond to your feelings and emotions about the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13.	help you manage the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.	help you cope with the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Dealing With Uncertainty

		Very Much	A Fair Amount	Somewhat	A Little	Not at All	Don't Know	Does Not Apply
To what extent does your doctor...								
15.	let you know about the uncertainties before you ask about them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16.	try to understand what you are uncertain about in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17.	comfort and reassure <u>you</u> about the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18.	comfort and reassure <u>your family or caregivers</u> about the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19.	explain the uncertainties of your cancer care in a way that is easy to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20.	help you handle the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21.	help you feel a sense of control in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Background / Demographics

Instructions: The next few questions ask about your cancer diagnosis and treatment.

1. When was the first time that a doctor or other healthcare professional told you that you had cancer?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

2. What type(s) of cancer have you ever been diagnosed with? (check all that apply)

- ☐ Bladder cancer
- ☐ Breast cancer
- ☐ Colorectal cancer (cancer of the colon or rectum)
- ☐ Endometrial cancer
- ☐ Hodgkin's lymphoma (or Hodgkin's Disease)
- ☐ Kidney cancer (renal cell)
- ☐ Leukemia

- ☐ Lung cancer
- ☐ Melanoma
- ☐ Non-Hodgkin lymphoma
- ☐ Pancreatic cancer
- ☐ Prostate cancer
- ☐ Skin cancer (other than melanoma)
- ☐ Other type of cancer (specify)

☐ Don't know

3. What is your cancer treatment status?

- ☐ I have not yet started my cancer treatment → Skip to Q6
- ☐ I am currently receiving treatment
- ☐ I have completed my active cancer treatment (can still be taking medication to prevent recurrence, or the cancer coming back),
- ☐ I will not receive cancer treatment (e.g., watchful waiting) → Skip to Q6

☐ Don't know

4. What type(s) of cancer treatment have you ever received? (Check all that apply)

- ☐ I have not received any medical treatment for cancer → Skip to Q6
- ☐ Surgery (do not consider biopsy or insertion of medication ports to be surgery)
- ☐ Chemotherapy (include both IV, that is intravenous, and oral forms of chemotherapy)
- ☐ Radiation therapy
- ☐ Hormonal therapy
- ☐ Bone marrow or stem cell transplant (do not consider bone marrow biopsy to be a transplant)
- ☐ Targeted, biologic and immune therapies
- ☐ Complementary or alternative medicine
- ☐ Other medical treatments (please specify)

☐ Don't know

5. When was the last time you received any of these treatments for your cancer?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

6. At any time since you were first diagnosed with cancer, did a doctor or other health care professional tell you that your cancer had come back (i.e., had a recurrence)?

- ☐ Yes
- ☐ No → Skip to Q8

7. [If yes] When was your most recent recurrence?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

The next questions ask about the main doctor who is treating (or treated) your cancer. Your main doctor is the doctor you consider to be in charge of your cancer care. If you have had more than one main doctor since you were first diagnosed with cancer, please answer these questions about your most recent main doctor.

8. What is your main doctor's area of specialty?

- ☐ Primary care (such as internal medicine, family practice),
 - ☐ Medical oncologist or hematologist
 - ☐ Radiation oncologist
 - ☐ Surgeon
 - ☐ Gastroenterologist
 - ☐ Dermatologist
 - ☐ Urologist
 - ☐ Other (please specify)
-
- ☐ Don't know

9. Is your main doctor male or female?

- ☐ Male
- ☐ Female

10. How long have you been going to this doctor for any kind of medical care?

- ☐ Less than 3 months
- ☐ More than 3 months but less than 12 months
- ☐ 1 to 2 years
- ☐ More than 2 years but less than 5 years
- ☐ 5 or more years

11. In the last 12 months, how many times did you see your main doctor?

- ☐ One time
- ☐ Two times
- ☐ Three times
- ☐ Four times
- ☐ Five to nine times
- ☐ Ten or more times

Recognizing and Responding to Emotions

Instructions: People diagnosed with cancer sometimes have different feelings throughout their cancer care. This set of questions asks about your communication with your doctor about your feelings.

Talking About Your Feelings

	Always	Often	Sometimes	Rarely	Never	Don't Know	Does Not Apply
How often do you and your doctor discuss...							
1 how you are coping with your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2 how you are coping with your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3 how you are coping with your feelings related to your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4 your feelings related to your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5 your feelings related to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6 things you can do to cope with your concerns and fears about cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Dealing With Your Feelings

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
7.	make you feel comfortable to talk about your fears, worries, or other feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
8.	seem to know if you are feeling sad or blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
9.	seem to know how you are coping with your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
10.	seem to know how you are coping with your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
11.	show that he or she is aware of your feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
12.	show that he or she is aware of your family's or caregiver's feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
13.	let you know that other patients with cancer often have feelings similar to yours?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
14.	show concern for your feelings, not just your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
15.	show concern about how you are doing emotionally?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
16.	show concern for how your family or caregiver is doing emotionally?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
17.	show sensitivity to your feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
18.	show an understanding of your concerns and fears about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
19.	reassure you about your concerns about cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
20.	reassure you about his or her commitment to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
21.	comfort and reassure you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
22.	show that he or she understands what it feels like to be in your situation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
23.	give you emotional support?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
24.	help you think about ways to deal with stress related to cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
25.	help you think about ways to deal with stress related to cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
26.	tell you about support groups or treatments that could help you deal with your emotions related to cancer and cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
27.	help you plan to get help (e.g., counseling, support groups, medications) to better cope with your emotions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
28.	suggest things you can do to cope with your concerns and fears about cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Crosscutting Domains

Communicating With Your Doctor

These questions ask about how your doctor communicates with you.

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
1.	listen carefully to what you have to say?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
2.	treat you with courtesy and respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
3.	treat your family or caregivers with courtesy and respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
4.	limit interruptions during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
5.	give you his or her full attention?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
6.	make sure there is privacy during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
7.	make sure he or she can focus on you during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
8.	spend enough time with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
9.	make the best use of the time with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
10.	take the time to address your questions and concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Roles and Responsibilities

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
11.	explain the roles and responsibilities of other healthcare providers involved in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
12.	explain who is in charge of your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
13.	seem to communicate with other healthcare providers so that they are up-to-date with test results and the cancer care you receive?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
14.	seem to work with other healthcare providers involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Managing Your Cancer, Your Treatment, and Your Health

Instructions: These questions focus on how you and your doctor talk about managing your cancer, your treatment, and your health, especially between visits to the doctor.

Cancer and Everyday Life

	Very Much	A Fair Amount	Somewhat	A Little	Not at All	Don't Know	Does Not Apply
To what extent do you and your doctor discuss...							
1. how cancer is affecting <u>you</u> everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. how your cancer care is affecting <u>you</u> everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. how cancer is affecting <u>your family's</u> everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. how your cancer care is affecting <u>your family's</u> everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Cancer Care

	Very Much	A Fair Amount	Somewhat	A Little	Not at All	Don't Know	Does Not Apply
To what extent do you and your doctor discuss...							
5. what is important to <u>you</u> when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. what is important to <u>your family or caregivers</u> when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. your ideas and preferences when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent does your doctor...								
8.	let you know when it's time to change your cancer care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.	discuss what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.	make sure <u>you</u> understand what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11.	make sure <u>your family or caregivers</u> understand what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent does your doctor...								
12.	check if you are having problems following your cancer care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13.	discuss how to deal with problems that make it hard to follow your cancer care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.	discuss how your family or caregiver can make it easier for you to follow your cancer care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Coordinating Your Cancer Care

		How well does your doctor...					Does Not Apply	
		Excellent	Very Good	Good	Fair	Poor	Don't Know	
15.	explain what steps are needed to get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
16.	coordinate with other healthcare providers to make sure you get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
17.	help you coordinate with other healthcare providers to get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>

		To what extent does your doctor...					Does Not Apply	
		Very Much	A Fair Amount	Somewhat	A Little	Not at All	Don't Know	
18.	ask you about the cancer care you receive from other healthcare providers?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
19.	discuss problems you might have in getting the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
20.	discuss how your culture might affect how your cancer care is delivered?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>

Appendix K. Objective 3: Screener

Patient-Centered Communication in Cancer Care

Cognitive Testing of Items – Recruitment Screener

INTRODUCTION

Hello. My name is _____, and I'm calling from [FACILITY NAME]. I'm calling on behalf of RTI International, a non-profit research organization in North Carolina. I'm not selling or promoting any product. Instead, I'm calling about a research study on healthcare.

The purpose of the study is to learn about patients' healthcare experiences and gather their feedback on tools that hospitals and clinics might use to evaluate the quality of cancer care.

To see if you're eligible for this study, I'd like to ask you a few questions. If you are eligible and wish to participate in the study, all of your answers will be kept confidential. If you choose to participate, we will compensate you for your time, effort, and travel expenses.

My questions will take only a few minutes. May I proceed?

Yes	<input type="checkbox"/>	➔ [Continue]
No	<input type="checkbox"/>	➔ [Terminate / Call back]

ELIGIBILITY

1. Have you ever been diagnosed with cancer?

Yes	<input type="checkbox"/>	➔ [Continue]
No	<input type="checkbox"/>	➔ [Terminate]

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2. With what type(s) of cancer were you diagnosed? [Mark all that apply.] **[Priority #4]**

<u>Cancer Type</u>		<u>Quota</u>
Breast	<input type="checkbox"/>	No more than 30%
Colorectal	<input type="checkbox"/>	No more than 30%
Kidney or Bladder	<input type="checkbox"/>	No more than 15%
Leukemia or Lymphoma	<input type="checkbox"/>	No more than 15%
Lung	<input type="checkbox"/>	No more than 30%
Ovarian, uterine, cervical, or endometrial	<input type="checkbox"/>	No more than 15%
Pancreatic	<input type="checkbox"/>	No more than 15%
Prostate	<input type="checkbox"/>	No more than 15%
Skin (melanoma)	<input type="checkbox"/>	No more than 15%
Skin (non-melanoma)	<input type="checkbox"/>	No more than 15%
Testicular	<input type="checkbox"/>	No more than 15%
Other or Unspecified Site	<input type="checkbox"/>	N/A

[If "Other"] Specify: _____

3A. When were you diagnosed with cancer? If you have been diagnosed with cancer more than once, please think about your most recent diagnosis.

[Request month/year. Assign to appropriate category.]

Month: _____ Year: _____

Within the last 3 months ☐ → [Continue to 3B]

More than 3 months ago ☐ → [Continue to 3C]

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3B. [IF MOST RECENT DIAGNOSIS WITHIN LAST 3 MONTHS] Have you started treatment for your cancer yet?

Yes ☐ → [Assign to Recently Diagnosed category]
No ☐ → [Terminate]

3C. [IF MOST RECENT DIAGNOSIS MORE THAN 3 MONTHS AGO] Are you currently receiving treatment for your cancer? By treatment, we mean chemotherapy, radiation, surgery, or other medical procedures that occurred in a clinical setting.

Yes ☐ → [Assign to Active Treatment category]
No ☐ → [Continue to 3D]

3D. When did you complete your most recent treatment?

[Request month/year. Assign to appropriate category.]

Month: _____ Year: _____

Within the last 6 months ☐ → [Assign to Post-Treatment category]
More than 6 months ago ☐ → [Terminate]

Cancer Phase **Priority #1**

Assign to appropriate category based on questions 3A-3D.

Cancer Phase

Recently Diagnosed

Active Treatment

Post-Treatment

☐
☐
☐

Quota

No more than 50%

No more than 50%

No more than 50%

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4. What is your sex? **[Priority #5]**

Sex

Male

☐

Female

☐

Quota

No more than 75%

No more than 75%

5. What is the highest level of education you have attained? **[Priority #2]**

Education Level

Less than high school

☐

High school graduate
(or GED)

☐

Some college

☐

Associate's degree

☐

Bachelor's degree

☐

Post-graduate degree

☐

Quota

At least 30%

At least 15%

(HS grad + Some college)

N/A

N/A

N/A

6. Which of these racial groups best describes you? [Read response options. Mark all that apply.]

[Priority #3]

Race

White

☐

Black / African American

☐

American Indian or Alaskan Native

☐

Asian

☐

Native Hawaiian or Pacific Islander

☐

Other

☐

Quota

No more than 75%

No more than 75%

No more than 75%

No more than 75%

No more than 75%

No more than 75%

INVITATION (ELIGIBLE)

Thank you for answering all of my questions.

Based on your responses, I would like to invite you to participate in an informal, personal interview. The purpose of the interview is to learn more about your healthcare experiences and to get your feedback on tools that hospitals and clinics might use to evaluate the quality of care.

The interview would last 90 minutes, would take place in [FACILITY CITY], **would be audio recorded**, and would be scheduled at a time convenient for you. No one will attempt to sell you anything, and no one will contact you about other studies as a result of your participation. We will compensate you \$150 for your time, effort, and travel expenses.

This is an important research study, and we would value your input. Can we schedule your attendance?

[If yes, consult available dates / times.]

TERMINATION (INELIGIBLE)

Thank you for answering all of my questions. Unfortunately, you're not eligible for the study at this time. However, I appreciate your interest and willingness to help us.

Appendix L. Objective 3: Consent Form

Patient-Centered Communication in Cancer Care Cognitive Testing

Consent Form

Introduction and Purpose

You have been invited to take part in a research study. The purpose of the study is to pre-test a survey on patients' cancer care experiences, including interactions with their doctor. RTI International, a non-profit research organization in North Carolina, is conducting the interview. The study is sponsored by the Agency for Healthcare Research and Quality (AHRQ).

Procedures

The study will consist of a 90-minute, one-on-one interview. During the interview, we will ask you to review and provide feedback on survey questions related to cancer care. If you agree, we also would like to audio record the interview to supplement our notes. The recording will be erased at the end of the project.

We will be interviewing approximately 54 patients in Raleigh-Durham, NC, and Washington, D.C.

Benefits

There is no direct benefit to you for participating. However, you may find the discussion interesting and informative. What we learn from the interview will be used to improve the survey.

Risks

There are no known risks for participating in this study. The questions we ask are not meant to be sensitive. However, there is a chance that talking about your cancer care experience may be uncomfortable.

Your participation in this study is voluntary. You may choose to skip any question that you do not want to answer, and you can stop participating at any time.

Confidentiality

Your feedback and participation in the study are confidential. Your responses will be combined with other participants' responses, and we will never identify you by name.

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Our interview notes will be kept in a locked file cabinet or on a password-protected computer. Any forms related to the project will be kept in a locked file cabinet.

Reimbursement

In appreciation for your time and travel, we will gladly reimburse you \$150 at the end of the interview.

Right to Refuse or Withdraw

Your participation in this study is voluntary. You can skip any question. You can end the interview and withdraw from the study for any reason at anytime.

Persons to Contact

If you have questions about the study, you may call the project director, Dr. Lauren McCormack, at 1-800-334-8571, ext. 6277 (toll-free). If you have questions about your rights as a participant, you can call RTI's Office of Research Protection toll-free at 1-866-214-2043.

Your Consent

I have read this consent form. I had a chance to ask questions, and my questions were answered. I was given a copy of this consent form. I agree to participate.

The above document describing the benefits, risks, and procedures for this research study has been explained to me. I agree to participate.

Signature of Subject

Date

Signature of Person Obtaining Consent

Date

I agree to be audio recorded (please mark your answer):

Yes _____

No _____

Appendix M. Objective 3: Patient Interview Guides

Exchanging Information

Instructions: The next few questions ask about the information that you and your main doctor might discuss.

Your Understanding and Preferences

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent do you and your doctor discuss...								
41. what you already know and understand about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
42. what you already know and understand about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
43. your concerns and questions about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
44. your concerns and questions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
45. how much information you would like to have about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
46. how much information you would like to have about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
47. any differences of opinions or beliefs about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
48. any differences of opinions or beliefs about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Your Opinions and Questions

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
49.	show interest in your cancer experience?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
50.	ask you to share your cancer experience with him or her?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
51.	make you feel comfortable asking questions or talking about your concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
52.	make it easy for you to share personal or sensitive information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
53.	listen carefully to what you have to say about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
54.	listen carefully to what you have to say about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
55.	check to be sure he or she understands what you say?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Information Given by Your Doctor

		Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
How often does your doctor...									
56.	give you helpful information, even when you don't ask for it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
57.	suggest information that is helpful to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
58.	make sure you have the information you need and want?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
59.	show you pictures, graphs, or other materials to help you understand important information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
60.	give you brochures, written information, or other materials to help you remember important information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
61.	give you materials (e.g., brochures, DVDs or videos, web sites) that are helpful to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
62.	tell you where you can get other information you need (e.g. from websites, organizations)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
63.	explain things in a way that is clear and easy to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
64.	explain information in different ways to help you understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
65.	help you understand the information you need to know about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
66.	help you understand the information you need to know about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
67.	make sure you understand important information about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
68.	make sure you understand important information about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
69.	check to be sure your questions are answered?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
70.	let you know if you misunderstood any information about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
71.	let you know if you misunderstood any information about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
72.	check to see what kinds of information you would like to have about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
73.	check to see what kinds of information you would like to have about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
74.	understand what kinds of materials (e.g., brochures, DVDs or videos, web sites) might be helpful for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
75.	discuss with you information that you get from other places (e.g., information you find on the Internet)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Sharing Difficult News

Sometimes, doctors have to share difficult (or “bad”) news with cancer patients.

76. Has your doctor has ever had to share any bad news with you about your cancer care?

- ☐ Yes → Go to 37
☐ No → Stop

- ☐ Don't know → Stop
☐ Does Not Apply → Stop

77. Has your doctor asked how you would like to learn about any bad news?

- ☐ Yes
☐ No

- ☐ Does Not Apply

78. Does your doctor share bad news with you in the way that you like?

- ☐ Yes
☐ No

- ☐ Does Not Apply

How well does your doctor share bad news...		Excellent	Very Good	Good	Fair	Poor		Don't Know	Does Not Apply
79.	in the way that is right for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
80.	in a way that is sensitive to your needs and feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Fostering Healing Relationships

The next few questions ask about things that your doctor may have done to build a good relationship with you. Specifically, the questions ask if you are treated as an individual, are given good explanations about roles/responsibilities for your care, and can speak openly / honestly with your doctor.

Care and Concern

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...								
35. show that he or she cares about you as an individual person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
36. show real interest in you as an individual person, not just in your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
37. try to get to know you as an individual person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
38. show real concern for you and your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
39. remember details about you between visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
40. treat you as an individual?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
41. treat you as a person, not just another patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
42. show that he or she cares about you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
43. show that he or she cares about your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
44. consider what is best for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
45. show commitment to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
46. show that he or she cares about your health needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
47. show interest in your background and culture?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Your Doctor's Role and Your Role

		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent do you and your doctor discuss...								
48.	how you will work together as a team during your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49.	his or her role in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50.	how you would like to be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51.	how you could be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52.	his or her desire for you to be actively involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53.	how you would like your family (or caregivers) to be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54.	how your family (or caregivers) could be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Communicating With Your Doctor

		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent do you and your doctor...								
55.	discuss the importance of open and honest communication?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56.	have open and honest communication, including differences of opinion?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57.	feel comfortable sharing information openly and honestly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58.	share information in a way that you prefer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
59.	share complete and honest information with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
60.	share information with your family (or caregiver) in a way that you prefer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
61.	share complete and honest information with your family (or caregiver)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent does your doctor talk in a way that makes you...								
62.	feel he or she is well informed about your type of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
63.	feel he or she is up-to-date with the latest treatment choices for your type of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
64.	feel confident in his or her ability to meet your cancer care needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
65.	trust in his or her ability to provide you with the care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
66.	trust him or her with personal or sensitive information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Does Not Apply	Don't Know	Poor	Fair	Good	Very Good	Excellent
How well does your doctor seem to communicate...								
67.	with other healthcare providers who help take care of you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
68.	with other healthcare providers to make sure that you get the care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Dealing with Mistakes

35. As far as you are aware, have there been any medical mistakes or errors in your cancer care?

- ☐ Yes → Go to 36A
- ☐ No → Skip to next section

- ☐ Don't Know → Skip to next section
- ☐ Does Not Apply → Skip to next section

35A. Did your doctor discuss the medical mistake or error with you?

- ☐ Yes → Continue
☐ No → Stop

- ☐ Does Not Apply → Stop

35B. How well did your doctor discuss the medical mistake or error with you?

- ☐ Excellent
☐ Very Good
☐ Good
☐ Fair
☐ Poor

- ☐ Does Not Apply

Recognizing and Responding to Emotions

Instructions: People diagnosed with cancer sometimes have different feelings throughout their cancer care. This set of questions asks about your communication with your doctor about your feelings.

Talking About Your Feelings

		Always	Often	Sometimes	Rarely	Never	Does Not Apply	Don't Know
How often do you and your doctor discuss...								
29.	how you are coping with your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30.	how you are coping with your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31.	how you are coping with your feelings related to your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32.	your feelings related to your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33.	your feelings related to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.	things you can do to cope with your concerns and fears about cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Dealing With Your Feelings

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
35.	make you feel comfortable to talk about your fears, worries, or other feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
36.	seem to know if you are feeling sad or blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
37.	seem to know how you are coping with your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
38.	seem to know how you are coping with your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
39.	show that he or she is aware of your feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
40.	show that he or she is aware of your family's or caregiver's feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
41.	let you know that other patients with cancer often have feelings similar to yours?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
42.	show concern for your feelings, not just your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
43.	show concern about how you are doing emotionally?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
44.	show concern for how your family or caregiver is doing emotionally?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
45.	show sensitivity to your feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
46.	show an understanding of your concerns and fears about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
47.	reassure you about your concerns about cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
48.	reassure you about his or her commitment to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
49.	comfort and reassure you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
50.	show that he or she understands what it feels like to be in your situation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
51.	give you emotional support?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
52.	help you think about ways to deal with stress related to cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
53.	help you think about ways to deal with stress related to cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
54.	tell you about support groups or treatments that could help you deal with your emotions related to cancer and cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
55.	help you plan to get help (e.g., counseling, support groups, medications) to better cope with your emotions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
56.	suggest things you can do to cope with your concerns and fears about cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Crosscutting

Communicating With Your Doctor

These questions ask about how your doctor communicates with you.

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
1.	listen carefully to what you have to say?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
2.	treat you with courtesy and respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
3.	treat your family or caregivers with courtesy and respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
4.	limit interruptions during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
5.	give you his or her full attention?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
6.	make sure there is privacy during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
7.	make sure he or she can focus on you during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
8.	spend enough time with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
9.	make the best use of the time with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
10.	take the time to address your questions and concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Roles and Responsibilities

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
11.	explain the roles and responsibilities of other healthcare providers involved in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
12.	explain who is in charge of your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
13.	seem to communicate with other healthcare providers so that they are up-to-date with test results and the cancer care you receive?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
14.	seem to work with other healthcare providers involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Managing Uncertainty

Introductions: During medical care, there may be situations where there is not a clear answer or where doctors and patients don't know the answer to an important question. For example, experts sometimes disagree about which treatment is best, or doctors cannot be sure which side effects will occur during treatment. These types of situations can cause uncertainty for patients.

The next section asks about the uncertainties you have experienced in your care. It also asks how you and your main doctor have discussed or dealt with these uncertainties.

2. What types of uncertainties have you experienced in the course of your cancer care? (Check all that apply.)

Types of uncertainties...

- | | |
|--|--------------------------|
| a. What is my diagnosis? | <input type="checkbox"/> |
| b. What is my prognosis? | <input type="checkbox"/> |
| c. What are the treatment choices? | <input type="checkbox"/> |
| d. Which treatment will be best for me? | <input type="checkbox"/> |
| e. What are the chances of my cancer coming back? | <input type="checkbox"/> |
| f. What kinds of side effects I will have from treatment? | <input type="checkbox"/> |
| g. How I will cope with side effects of treatment? | <input type="checkbox"/> |
| h. Where should I go for treatment? | <input type="checkbox"/> |
| i. How do I choose a doctor? | <input type="checkbox"/> |
| j. What do different doctors and health care providers do? | <input type="checkbox"/> |
| k. Will health insurance cover my treatment? | <input type="checkbox"/> |
| l. Will I be able to work during (or after) treatment? | <input type="checkbox"/> |
| m. Can I carry out my family responsibilities during (or after) treatment? | <input type="checkbox"/> |
| n. Can I continue with my usual activities during (or after) treatment? | <input type="checkbox"/> |
| o. How will cancer affect my everyday life? | <input type="checkbox"/> |
| p. How should I tell my family or friends about my cancer? | <input type="checkbox"/> |
| q. What are my rights as a patient? | <input type="checkbox"/> |
| r. What is my role in making decisions about my care? | <input type="checkbox"/> |
| s. What is my family's role in making decisions about my care? | <input type="checkbox"/> |
| t. Other issues or situations | <input type="checkbox"/> |

Please specify: _____

2. Has your doctor ever told you that sometimes there are uncertainties in cancer care? ☐ Yes ☐ No

	Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
How often do you and your doctor...								
3. discuss uncertainties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
4. discuss your questions about the uncertainties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Reasons for Uncertainty

	Excellent	Very Good	Good	Fair	Poor		Don't Know	Does Not Apply
How well does your doctor...								
5. identify possible sources of uncertainty in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
6. explain the reasons for uncertainty in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
7. share the information you want about the uncertainties that affect your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
8. help you make sense of the uncertainties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
9. explain uncertainties caused by experts not having enough information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
10. explain the uncertainties that experts disagree about?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
11. help you understand <u>why</u> experts have different opinions about your type of cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
12. respond to your feelings and emotions about the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
13. help you manage the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
14. help you cope with the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Dealing With Uncertainty

		Very Much	A Fair Amount	Somewhat	A Little	Not at All			Don't Know	Does Not Apply
To what extent does your doctor...										
15.	let you know about the uncertainties before you ask about them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
16.	try to understand what you are uncertain about in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
17.	comfort and reassure <u>you</u> about the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
18.	comfort and reassure <u>your family or caregivers</u> about the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
19.	explain the uncertainties of your cancer care in a way that is easy to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
20.	help you handle the uncertainties of your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
21.	help you feel a sense of control in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>

Background / Demographics

Instructions: The next few questions ask about your cancer diagnosis and treatment.

12. When was the first time that a doctor or other healthcare professional told you that you had cancer?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

13. What type(s) of cancer have you ever been diagnosed with? (check all that apply)

- ☐ Bladder cancer
- ☐ Breast cancer
- ☐ Colorectal cancer (cancer of the colon or rectum)
- ☐ Endometrial cancer
- ☐ Hodgkin's lymphoma (or Hodgkin's Disease)
- ☐ Kidney cancer (renal cell)
- ☐ Leukemia
- ☐ Lung cancer
- ☐ Melanoma
- ☐ Non-Hodgkin lymphoma
- ☐ Pancreatic cancer

- ☐ Prostate cancer
- ☐ Skin cancer (other than melanoma)
- ☐ Other type of cancer (specify)

☐ Don't know

14. What is your cancer treatment status?

- ☐ I have not yet started my cancer treatment → Skip to Q6
- ☐ I am currently receiving treatment
- ☐ I have completed my active cancer treatment (can still be taking medication to prevent recurrence, or the cancer coming back),
- ☐ I will not receive cancer treatment (e.g., watchful waiting) → Skip to Q6

☐ Don't know

15. What type(s) of cancer treatment have you ever received? (Check all that apply)

- ☐ I have not received any medical treatment for cancer → Skip to Q6
- ☐ Surgery (do not consider biopsy or insertion of medication ports to be surgery)
- ☐ Chemotherapy (include both IV, that is intravenous, and oral forms of chemotherapy)
- ☐ Radiation therapy
- ☐ Hormonal therapy
- ☐ Bone marrow or stem cell transplant (do not consider bone marrow biopsy to be a transplant)
- ☐ Targeted, biologic and immune therapies
- ☐ Complementary or alternative medicine
- ☐ Other medical treatments (please specify)

☐ Don't know

16. When was the last time you received any of these treatments for your cancer?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

17. At any time since you were first diagnosed with cancer, did a doctor or other health care professional tell you that your cancer had come back (i.e., had a recurrence)?

- ☐ Yes
- ☐ No → Skip to Q8

18. [If yes] When was your most recent recurrence?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

Effective Health Care Program Research Report Number 39

The next questions ask about the main doctor who is treating (or treated) your cancer. Your main doctor is the doctor you consider to be in charge of your cancer care. If you have had more than one main doctor since you were first diagnosed with cancer, please answer these questions about your most recent main doctor.

19. What is your main doctor's area of specialty?

- ☐ Primary care (such as internal medicine, family practice),
- ☐ Medical oncologist or hematologist
- ☐ Radiation oncologist
- ☐ Surgeon
- ☐ Gastroenterologist
- ☐ Dermatologist
- ☐ Urologist
- ☐ Other (please specify)

- ☐ Don't know

20. Is your main doctor male or female?

- ☐ Male
- ☐ Female

21. How long have you been going to this doctor for any kind of medical care?

- ☐ Less than 3 months
- ☐ More than 3 months but less than 12 months
- ☐ 1 to 2 years
- ☐ More than 2 years but less than 5 years
- ☐ 5 or more years

22. In the last 12 months, how many times did you see your main doctor?

- ☐ One time
- ☐ Two times
- ☐ Three times
- ☐ Four times
- ☐ Five to nine times
- ☐ Ten or more times

Making Decisions

Instructions: There are often many different decisions to be made in cancer care, for example, decisions about treatment choices or where to go for care. These questions ask about how you and your doctor discuss and make decisions about your care.

Involvement in Making Decisions

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent do you and your doctor discuss...									
1.	how much <u>you</u> want to be involved in making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
2.	how much you want <u>your family or caregivers</u> to be involved in making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
3.	what matters most to <u>you</u> when making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
4.	what matters most to <u>your family or caregivers</u> when making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
5.	what kinds of support would be helpful to you in making decisions (e.g., talking with other patients, talking with other healthcare providers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
6.	how different treatment choices would affect <u>you</u> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
7.	how different treatment choices would affect <u>your family or caregivers</u> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
8.	his or her recommendations for your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Understanding Decisions

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
9.	make it clear when there are decisions to be made about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
10.	explain the different choices in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
11.	explain the advantages and disadvantages of different treatment choices, before making decisions about your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
12.	explain the risks and benefits of different choices, before making decisions about your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
13.	check how well you understand the different choices in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
14.	show interest in what you have to say about the different choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
15.	suggest ways you can be involved in making decisions about your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
16.	suggest things to think about that help you make decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
17.	share the information you need to help you make decisions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
18.	share materials (e.g., brochures or other written materials, DVDs or videos, web sites) to help you in making decisions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Excellent	Very Good	Good	Fair	Poor		Don't Know	Does Not Apply
How well does your doctor...									
19.	explain the different choices in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
20.	answer your questions about different treatment options?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
21.	explain the advantages and disadvantages of different treatment choices, before making decisions about your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
22.	explain the risks and benefits of different choices, before making decisions about your care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
23.	explain his or her recommendations for your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

After Making Decisions

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
After making decisions about your cancer care, to what extent does your doctor...									
24.	review decisions to make sure you understand them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
25.	confirm your agreement with the decision before moving on to other issues?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
26.	check that you understand what the decision will mean for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
27.	check that you understand what the decision will mean for your family (or caregivers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
28.	ask if you are satisfied with how the decision was made?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
After making decisions about your cancer care, to what extent do you and your doctor discuss....								
29.	any questions you have about taking the next steps in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30.	what the decision will mean for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31.	what the decision will mean for your family (or other caregivers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32.	any problems you might have carrying out the decision?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

After Carrying Out Decisions

These next questions ask about your discussion with your doctor after you have had a chance to carry out a decision.

		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent do you and your doctor discuss...								
33.	how the decision worked out for <u>you</u> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.	how the decision worked out for <u>your family or caregivers</u> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35.	how the decision affected your quality of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36.	any problems you had in carrying out the decision?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37.	whether to make any changes to the decision?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Managing Your Cancer, Your Treatment, and Your Health

Instructions: These questions focus on how you and your doctor talk about managing your cancer, your treatment, and your health, especially between visits to the doctor.

Cancer and Everyday Life

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent do you and your doctor discuss...							
1. how cancer is affecting <u>your</u> everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. how your cancer care is affecting <u>your</u> everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. how cancer is affecting <u>your family's</u> everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. how your cancer care is affecting <u>your family's</u> everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Cancer Care

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
To what extent do you and your doctor discuss...							
5. what is important to <u>you</u> when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. what is important to <u>your family or caregivers</u> when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. your ideas and preferences when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		To what extent does your doctor...					Does Not Apply	
		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know
8.	let you know when it's time to change your cancer care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
9.	discuss what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
10.	make sure <u>you</u> understand what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
11.	make sure <u>your family or caregivers</u> understand what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>

		To what extent does your doctor...					Does Not Apply	
		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know
12.	check if you are having problems following your cancer care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
13.	discuss how to deal with problems that make it hard to follow your cancer care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
14.	discuss how your family or caregiver can make it easier for you to follow your cancer care plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>

Coordinating Your Cancer Care

		Excellent	Very Good	Good	Fair	Poor		Don't Know	Does Not Apply
How well does your doctor...									
15.	explain what steps are needed to get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
16.	coordinate with other healthcare providers to make sure you get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
17.	help you coordinate with other healthcare providers to get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor...									
18.	ask you about the cancer care you receive from other healthcare providers?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
19.	discuss problems you might have in getting the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
20.	discuss how your culture might affect how your cancer care is delivered?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Informational Resources

In some cases, doctors help patients find resources to help them manage their health during and after their cancer care.

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent does your doctor help you find resources for...									
21.	managing your own health (i.e., help with diet, exercise, stress)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
22.	getting the cancer care you need (i.e., help with transportation, cost of medications)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Managing Your Own Health

In some cases, doctors discuss ways that you can manage your own health during and after your cancer care.

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
To what extent do you and your doctor discuss...									
23.	the goals for your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
24.	changes you can make to take better care of your health (such as diet, exercise, dealing with stress)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
25.	ways you can manage your side effects or symptoms?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
26.	ways you can take care of yourself at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
27.	ways that your family or caregivers can take care of you at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
28.	questions or concerns you have about managing your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
29.	the kinds of support you need to manage your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
How often do you and your doctor discuss...									
30.	ways to manage your own health (such as diet, exercise, dealing with stress)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
31.	ideas for managing your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
32.	how you are doing with your goals for managing your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Appendix N. Objective 3: Summary Findings and Recommendations: Exchanging Information

Exchanging information (9 respondents)

Question Number	Current Wording	Findings	Recommendations	Additional Notes
Instructions	The next few questions ask about the information that you and your main doctor might discuss.	Most participants identified multiple providers but had no real difficulty identifying their “main doctor.”	—	—
1	To what extent do you and your doctor discuss...what you already know and understand about your cancer?	Patients understood the distinction between “cancer” and “cancer care.”	—	Question is particularly relevant to patients in early treatment. After they have a relationship with their doctor and started treatment, this does not appear to be as relevant. Continue using the phrase “cancer care” in the measurement items.
2	To what extent do you and your doctor discuss...what you already know and understand about your cancer care?	Patients understood the distinction between “cancer” and “cancer care.” Patients preferred the terms “cancer care” instead of “cancer treatment.” Care was interpreted as encompassing the entire continuum—diagnosis, treatment, and follow up.	—	Question is particularly relevant to patients in early treatment. After they have a relationship with their doctor and started treatment, this does not appear to be as relevant. Continue using the phrase “cancer care” in the measurement items.
3	To what extent do you and your doctor discuss...your concerns and questions about your cancer?	No problems.	—	—
4	To what extent do you and your doctor discuss...your concerns and questions about your cancer care?	No problems. Participants demonstrated an understanding of the differences between Q1 through Q4.	—	—
5	To what extent do you and your doctor discuss...how much information you would like to have about your cancer?	Two of nine participants lost track of the stem. However, when prompted, they appropriately incorporated the stem into the question and their response. No other problems were noted.	—	Emphasize the stem by using color or other visual cues to help it stand out more clearly.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
6	To what extent do you and your doctor discuss...how much information you would like to have about your cancer care?	No problems.	—	—
7	To what extent do you and your doctor discuss...any differences of opinions or beliefs about your cancer?	This question seems to be somewhat confusing overall. Four of nine participants were confused by the wording of this question, indicating that they were not sure if the differences of opinion referred to doctor–patient or doctor–doctor communication. A few participants also indicated that they trust their doctor to be right, so they never really see any differences of opinion in their interaction with their doctor.	Drop question.	—
8	To what extent does your doctor...any differences of opinions or beliefs about your cancer care?	This question seems to be somewhat confusing overall. Four of nine participants were confused by the wording of this question, indicating that they were not sure if the differences of opinion referred to doctor–patient or doctor–doctor communication. A few participants also indicated that they trust their doctor to be right, so they never really see any differences of opinion in their interaction with their doctor.	Drop question.	—
9	To what extent does your doctor...show interest in your cancer experience?	The concept of cancer experience was meaningful to the participant and understood in the manner intended. No problems were noted.	—	—
10	To what extent does your doctor...ask you to share your cancer experience with him or her?	The concept of cancer experience was meaningful to the participant and understood in the manner intended. No problems.	—	A number of participants indicated that their doctor does not directly ask about their “cancer experience” but that they believe their doctor knows and understands their experience. Keep this question, but note that is may be less meaningful than Q9.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
11	To what extent does your doctor...make you feel comfortable asking questions or talking about your concerns?	No problems. Participants were able to identify appropriate examples of times when they had questions and their doctor made them feel comfortable to ask questions.	—	—
12	To what extent does your doctor...make it easy for you to share personal or sensitive information?	Participants understood the intended meaning of “personal and sensitive” in the question and felt that the current wording was clear and understandable. No problems.	—	—
13	To what extent does your doctor...listen carefully to what you have to say about your cancer?	Patients understood the distinction between “cancer” and “cancer care.” No problems.	—	—
14	To what extent does your doctor...listen carefully to what you have to say about your cancer care?	Patients understood the distinction between “cancer” and “cancer care.” No problems.	—	—
15	To what extent does your doctor...check to be sure he or she understands what you say?	A third of participants indicated that the question sounded a bit strange to them. In particular the notion that their doctor would check their understanding of what they say. Most felt that what they say is understood by their doctor and no additional effort is needed to explore whether they understand. No other problems were noted.	Drop question.	May consider dropping, although this question addresses an important communication behavior. We would recommend keeping but to flag this question for future testing.
16	How often does your doctor...give you helpful information, even when you don't ask for it?	Some participants indicated that their doctor rarely provides information of this sort; this information is, instead, given primarily by a nurse or other staff member. No other problems were noted.	—	—
17	How often does your doctor...suggest information that is helpful to you?	No problems.	—	—
18	How often does your doctor...make sure you have the information you need and want?	No problems were noted.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
19	How often does your doctor...show you pictures, graphs, or other materials to help you understand important information?	No problems were noted. Participants were able to identify a range of materials that their doctors have used or could use to communicate with them.	—	—
20	How often does your doctor...give you brochures, written information, or other materials to help you remember important information?	See Q21.	Drop question.	—
21	How often does your doctor...give you materials (e.g., brochures, DVDs or videos, web sites) that are helpful to you?	Participants were able to identify a range of materials that their doctors have used or could use to communicate with them. Participants were able to accurately identify the differences between this question and Q17. Several participants noted that their doctor often does not “give” them materials, but rather makes them aware of available materials. Also, although the examples were helpful, none of the participants had ever been given a DVD or video by their doctor for information. Although they felt that the examples were helpful, participants felt that this issue had been covered in Q20.	How often does your doctor...give you or tell you about brochures, written information, or other materials that are helpful to you?	If retaining this question, we recommend deleting the reference to DVDs or videos and replacing it with written information or some other description.
22	How often does your doctor...tell you where you can get other information you need (e.g. from websites, organizations)?	No problems.	—	—
23	How often does your doctor...explain things in a way that is clear and easy to understand?	No problems.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
24	How often does your doctor...explain information in different ways to help you understand?	Very mixed responses from participants. Some felt that the question was clear and useful, while others felt that the question referred to the doctor "talking down" to them since they were not able to understand the information. Participants were able to provide adequate explanations for what was meant by "explain in a different way."	Drop question.	—
25	How often does your doctor...help you understand the information you need to know about your cancer?	No problems.	—	—
26	How often does your doctor...help you understand the information you need to know about your cancer care?	No problems.	—	—
27	How often does your doctor...make sure you understand important information about your cancer?	Although this question was clear and understandable, almost half of the respondents felt that it was redundant with Q25. The previous question is slightly different, focusing on "helping" them understand rather than "making sure" they understand, but it was not seen as very different. Participants felt that their doctor's did not check for understanding other than asking if they had any questions, so the question seemed out of place and unnatural to them. However, this question addresses an important element of PCC in cancer care, so it should be retained.	Drop question.	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
28	How often does your doctor...make sure you understand important information about your cancer care?	Although this question was clear and understandable, almost half of the respondents felt that it was redundant with Q26. The previous question is slightly different, focusing on "helping" them understand rather than "making sure" they understand, but it was not seen as very different. Participants felt that their doctors did not check for understanding other than asking if they had any questions, so the question seemed out of place and unnatural to them. However, this question addresses an important element of PCC in cancer care, so it should be retained.	Drop question.	—
29	How often does your doctor...check to be sure your questions are answered?	No problems.	—	—
30	How often does your doctor...let you know if you misunderstood any information about your cancer?	Approximately half of the participants indicated that they had concerns about this question. In particular, they were not sure how their doctor might know that they misunderstood any information about their cancer. Although difficult for these participants, they were all able to respond appropriately. It appears that in these cases some questions may not work as well because of personal factors associated with them rather than the questions themselves.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
31	How often does your doctor...let you know if you misunderstood any information about your cancer care?	Approximately half of the participants indicated that they had concerns about this question. In particular, they were not sure how their doctor might know that they misunderstood any information about either cancer care. Although difficult for these participants, they were all able to find an appropriate response. It appears that in these cases the question may not work as well because of personal factors associated with them rather than the question itself.	—	—
32	To what extent does your doctor...check to see what kinds of information you would like to have about your cancer?	No problems.	—	Question is particularly relevant to patients in early treatment. After they have a relationship and started treatment, this does not appear to be as relevant.
33	To what extent does your doctor...check to see what kinds of information you would like to have about your cancer care?	No problems.	—	Question is particularly relevant to patients in early treatment. After they have a relationship and started treatment, this does not appear to be as relevant.
34	To what extent does your doctor...understand what kinds of materials (e.g., brochures, DVDs or videos, web sites) might be helpful for you?	Several participants commented this question was repetitive with earlier questions (especially Q20 and Q21). Several participants suggested moving the examples in the parentheses to the end of the question where they would not be distracting. Participants were able to identify a number of examples of materials that they have received from their doctor in the past. None of the participants indicated that their doctors had ever used DVDs or videos.	Drop question.	

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
35	To what extent does your doctor...discuss with you information that you get from other places (e.g., information you find on the Internet)?	No problems. Participants were able to identify a number of examples of Web sites that contain information they have discussed with their doctor in the past.	—	—
36	Has your doctor ever had to share any bad news with you about your cancer care?	The terms “difficult” and “bad” were seen as being fairly interchangeable by most participants. They did recognize the difference between the terms but felt that if they were both used in the introduction, then the intended meaning was clear. At least one participant indicated that they wondered why the question focused on cancer care rather than cancer in general.	Has your doctor ever had to share any bad news with you about your cancer?	—
37	Has your doctor asked how you would like to learn about any bad news?	No problems.	—	—
38	Does your doctor share bad news with you in the way that you like?	No problems.	—	—
39	How well does your doctor share bad news...in the way that is right for you?	This question was understood correctly by the majority of participants. However, in a few cases, participants indicated that the phrase “in a way that is right for you?” seemed strange. Given the context of the next question, most of these participants thought that this might refer to the setting (e.g., in person vs. over the phone), but it was not clear.	Drop question.	—
40	How well does your doctor share bad news...in a way that is sensitive to your needs and feelings?	Although the phrasing of this question seemed a “bit strange” to some participants, no particular problems were noted.	—	—

Appendix O. Objective 3: Summary Findings and Recommendations: Fostering Healing Relationships

Fostering healing relationships (8 respondents)

Question Number	Current Wording	Findings	Recommendations	Additional Notes
Instructions	The next few questions ask about things that your doctor may have done to build a good relationship with you. Specifically, the questions ask if you are treated as an individual, are given good explanations about roles/responsibilities for your care, and can speak openly/honestly with your doctor.		—	—
1	To what extent does your doctor...show that he or she cares about you as an individual person?	No problems.	Consider dropping one or more of Q1, Q2, Q3, Q6, and Q7.	A few respondents noted overlap with other questions in this set.
2	To what extent does your doctor...show real interest in you as an individual person, not just in your illness?	No problems.	As above.	One respondent prefers this question to Q1 because “not just in your illness” clarifies meaning.
3	To what extent does your doctor...try to get to know you as an individual person?	No problems.	As above.	A few respondents noted overlap with other questions in this set.
4	To what extent does your doctor...show real concern for you and your health?	No problems.	—	A few respondents noted overlap with other questions in this set.
5	To what extent does your doctor...remember details about you between visits?	No problems. Interpreted as doctor remembering both medical and nonmedical information about them.	—	—
6	To what extent does your doctor...treat you as an individual?	No problems.	Drop question (overlap with Q7, which is more specific).	A few respondents noted overlap with other questions in this set.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
7	To what extent does your doctor...treat you as a person, not just another patient?	No problems.	As above.	A few respondents noted overlap with other questions in this set. One person prefers this question to Q6.
8	To what extent does your doctor...show that he or she cares about you?	No problems. Answers in terms of doctor devoting enough time, being responsive, considerate of comfort.	—	—
9	To what extent does your doctor...show that he or she cares about your family?	No problems.	Drop question.	In response to other questions about family/caregivers, participants indicate that this is lower high priority
10	To what extent does your doctor...consider what is best for you?	No problems.	—	A few respondents noted overlap with other questions in this set.
11	To what extent does your doctor...show commitment to your cancer care?	No problems. Interpretation of “commitment to your cancer care”: “being there,” responsive, knowing/taking care of what needs to be done, addressing concerns, caring.	Add a question to ask specifically about perceptions of the doctor's commitment to the patient's ongoing care, for example, “To what extent does your doctor show commitment to taking care of you for the long term/for as long as needed?”	Interpretation varied somewhat and did not include the nonabandonment concept.
12	To what extent does your doctor...show that he or she cares about your health needs?	No problems. Interpreted this as referring to health needs generally, not just cancer related.	—	—
13	To what extent does your doctor...show interest in your background and culture?	Most consider background and culture to be different, but some overlap: <ul style="list-style-type: none"> • Background: where you are from, personal/family history, career and activities (two interpreted as family health history). • Culture: religion, morals, values, family background. Two respondents said they would answer differently for each.	Further testing required. Consider separating into two questions: To what extent does your doctor show interest in your personal background? To what extent does your doctor show interest in your culture?	Most respondents said it is not important to them to discuss (nonmedical) background and culture.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
14	To what extent do you and your doctor discuss...how you will work together as a team during your cancer care?	Two respondents ignored stem and answered in terms of whether they, in fact, worked as a team, not whether they discussed working as a team. One participant found "as a team" unclear.	Highlight stem or move "discuss" from stem into question.	—
15	To what extent do you and your doctor discuss...his or her role in your cancer care?	Three respondents ignored stem, confused about how to interpret.	Highlight stem or move "discuss" from stem into question.	—
16	To what extent do you and your doctor discuss...how you would like to be involved in your cancer care?	Five respondents ignored stem, answered in terms of how involved they want to be not whether discussed how involved they want to be.	Highlight stem or move "discuss" from stem into question.	—
17	To what extent do you and your doctor discuss...how you could be involved in your cancer care?	Don't distinguish (or confused by difference) between Q16 and Q17 (same issues regarding stem).	Drop question.	—
18	To what extent do you and your doctor discuss...his or her desire for you to be actively involved in your cancer care?	Two respondents ignored stem. Interpreted "actively involved" in terms of self-care behaviors, adherence to treatment.	Highlight stem or move "discuss" from stem into question.	—
19	To what extent do you and your doctor discuss...how you would like your family (or caregivers) to be involved in your cancer care?	Three respondents ignored stem, answered in terms of how much they want family to be involved, not whether discussed family involvement. Interpreted "caregiver" as family or friend who helps them; one said can be paid or unpaid.	Highlight stem or move "discuss" from stem into question.	—
20	To what extent do you and your doctor discuss...how your family (or caregivers) could be involved in your cancer care?	Do not distinguish (or confused by difference) between Q19 and Q20 (same issues regarding stem).	Drop question.	—
21	To what extent do you and your doctor...discuss the importance of open and honest communication?	Four respondents say this is not discussed/do not feel need to discuss, unsure how to respond.	To what extent does your doctor...encourage you to share information openly and honestly?	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
22	To what extent do you and your doctor...have open and honest communication, including differences of opinion?	Three respondents had not had differences of opinion (others only came up with examples after probing); unsure how to respond if felt communication open/honest yet no differences of opinion.	Drop "differences of opinion" or focus question specifically on differences of opinion: Have open and honest communication? Discuss differences of opinion openly and honestly?	—
23	To what extent do you and your doctor...feel comfortable sharing information openly and honestly?	No problems.	—	Patient can't assess what doctor feels. Change stem to "To what extent do you...."
24	To what extent do you and your doctor...share information in a way that you prefer?	"In a way that you prefer" was confusing to several participants (one interpreted as what she wanted to hear).	Drop question.	[Error in stem: should be "To what extent does your doctor...".]
25	To what extent do you and your doctor...share complete and honest information with you?	No problems.	Correct stem.	[Error in stem: should be "To what extent does your doctor...".]
26	To what extent do you and your doctor...share information with your family (or caregiver) in a way that you prefer?	Several ignored "in a way that you prefer"; just answered whether doctor shared information with family.	Drop question.	[Error in stem: should be "To what extent does your doctor...".] Overlaps Q26 and Q27.
27	To what extent do you and your doctor...share complete and honest information with your family (or caregiver)?	No problems.	—	[Error in stem: should be "To what extent does your doctor...".] Overlaps Q26 and Q27.
28	To what extent does your doctor talk in a way that makes you...feel he or she is well informed about your type of cancer?	No problems.	—	—
29	To what extent does your doctor talk in a way that makes you...feel he or she is up-to-date with the latest treatment choices for your type of cancer?	No problems.	—	—
30	To what extent does your doctor talk in a way that makes you...feel confident in his or her ability to meet your cancer care needs?	No problems.	Drop question.	Overlap between Q30 and Q31 (trust and confidence the same). Drop Q30 as more complex.
31	To what extent does your doctor talk in a way that makes you...trust in his or her ability to provide you with the care you need?	No problems.	—	Overlap between Q30 and Q31 (perceive trust and confidence as the same).

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
32	To what extent does your doctor talk in a way that makes you...trust him or her with personal or sensitive information?	No problems.	—	—
33	How well does your doctor seem to communicate...with other healthcare providers who help take care of you?	No problems.	Move to cross-cutting domains.	[Note similarity to Q13 and Q14 in cross-cutting].
34	How well does your doctor seem to communicate...with other healthcare providers to make sure that you get the care you need?	No problems.	Move to cross-cutting domains.	[Note similarity to Q13 and Q14 in cross-cutting].
35	As far as you are aware, have there been any medical mistakes or errors in your cancer care?	Several missed skipped pattern instructions. Interpretation: Medical error = wrong medication or dosing, wrong or unneeded treatment, misinterpreted lab results, misdiagnosis, surgical error. (One not sure if includes HAI, and one not sure if includes "minor" errors).	Highlight skip instructions. Consider adding a definition of medical mistakes or errors to clarify that can include more/less serious events.	—
35a	Did your doctor discuss the medical mistake or error with you?	No problems.	—	—
35b	How well did your doctor discuss the medical mistake or error with you?	No problems.	—	—

Appendix P. Objective 3: Summary Findings and Recommendations: Recognizing and Responding to Emotions

Recognizing and responding to emotions (7 respondents)

Question Number	Current Wording	Findings	Recommendations	Additional Notes
Instructions	People diagnosed with cancer sometimes have different feelings throughout their cancer care. This set of questions asks about your communication with your doctor about your feelings.	No problems.	—	—
1	How often do you and your doctor discuss...how you are coping with your cancer?	Respondents said that changing the wording to “coping emotionally” would make the question clearer.	How often do you and your doctor discuss...how you are <u>coping emotionally</u> with your cancer?	—
2	How often do you and your doctor discuss...how you are coping with your cancer care?	Most participants identified a difference between “cancer” and “cancer care.” However, there was no consistency and quite a bit of variation between their definitions.	How often do you and your doctor discuss...how you are <u>coping emotionally</u> with your cancer care?	—
3	How often do you and your doctor discuss...how you are coping with your feelings related to your cancer?	No problems.	—	—
4	How often do you and your doctor discuss...your feelings related to your cancer?	No problems.	—	—
5	How often do you and your doctor discuss...your feelings related to your cancer care?	No problems overall. One respondent indicated that he and his doctor do not discuss feelings related to cancer care. One respondent said this was the same as Q4.	—	—
6	How often do you and your doctor discuss...things you can do to cope with your concerns and fears about cancer?	Several respondents see this question as distinct from Q1, because it is more specific than Q1. One respondent saw Q1 and Q6 as being similar.	—	—
7	To what extent does your doctor...make you feel comfortable to talk about your fears, worries, or other feelings?	No problems.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
8	To what extent does your doctor...seem to know if you are feeling sad or blue?	No problems with question or phrase "seem to know." Several respondents indicated the doctor would only know this if they told the doctor they felt this way.	—	—
9	To what extent does your doctor...seem to know how you are coping with your cancer?	Four respondents had no problems. Two respondents felt this question was redundant (one indicated it was the same as Q8).	Drop question (overlaps with Q1, which is preferable because it focuses on communication).	Explain use of cancer vs. cancer care in introduction.
10	To what extent does your doctor...seem to know how you are coping with your cancer care?	Four respondents had no problems. One interpreted question as being about physical response to cancer treatment. Two said question is same as Q8 and Q9.	Drop question (overlaps with Q2, which is preferable because it focuses on communication).	Explain use of cancer vs. cancer care in introduction.
11	To what extent does your doctor...show that he or she is aware of your feelings?	Most respondents had no problems. One said question was redundant.	—	—
12	To what extent does your doctor...show that he or she is aware of your family's or caregiver's feelings?	Most respondents had no problems. One indicated this question was only relevant when she was in active treatment, but not now that she is only receiving follow-up care. Some confusion regarding the meaning of the term "caregiver."	Drop Q12 because it overlaps with Q16. Q16 is broader because awareness is encompassed in "show concern."	—
13	To what extent does your doctor...let you know that other patients with cancer often have feelings similar to yours?	Most respondents had no problems.	—	—
14	To what extent does your doctor...show concern for your feelings, not just your illness?	Most respondents had no problems.	—	—
15	To what extent does your doctor...show concern about how you are doing emotionally?	No problems. Two respondents thought this question was the same as Q14.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
16	To what extent does your doctor...show concern for how your family or caregiver is doing emotionally?	No problems. One respondent indicated this question was similar to Q12. Two respondents indicated this question was not relevant because did not need a caregiver or family was involved earlier on, but not at current stage.	—	—
17	To what extent does your doctor...show sensitivity to your feelings?	No problems.	—	—
18	To what extent does your doctor...show an understanding of your concerns and fears about your cancer?	No problems.	—	—
19	To what extent does your doctor...reassure you about your concerns about cancer?	Most respondents had no problems. One was not sure how to think about this question. One felt this question was repetitive.	—	—
20	To what extent does your doctor...reassure you about his or her commitment to your cancer care?	No problems.	—	—
21	To what extent does your doctor...comfort and reassure you?	Most respondents had no problems. Several respondents indicated that this occurred, not through direct communication, but by just seeing the doctor or knowing it is possible to contact the doctor whenever necessary.	—	—
22	To what extent does your doctor...show that he or she understands what it feels like to be in your situation?	Three respondents indicated this was not relevant or applicable because the doctor could not know what it was really like because the doctor had not experienced it. One respondent mentioned that the doctor references other patients, not herself. Other respondents answered this question in terms of whether the doctor showed that he or she understood.	Drop question.	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
23	To what extent does your doctor...give you emotional support?	Most respondents had no problems. One respondent said this was the same as Q21. Other respondents indicated the doctor delegated emotional support to other professionals (e.g., through referral to psychiatrist) or by just spending time talking with the patient.	—	Consider adding a question about whether doctor ensures that patient gets emotional support from other sources.
24	To what extent does your doctor...help you think about ways to deal with stress related to cancer?	No problems.	—	—
25	To what extent does your doctor...help you think about ways to deal with stress related to cancer care?	Three respondents thought this question was the same as Q24. One respondent was unclear about what “cancer care” referred to.	—	—
26	To what extent does your doctor...tell you about support groups or treatments that could help you deal with your emotions related to cancer and cancer care?	Most respondents had no problems. One respondent indicated she had received this information from a nurse.	—	—
27	To what extent does your doctor...help you plan to get help (e.g., counseling, support groups, medications) to better cope with your emotions?	Respondents seemed to interpret this question in the same way as Q26. Two respondents indicated this question was the same as Q24 and Q26. Two respondents indicated that this occurred initially but was no longer relevant.	Drop Q27 because wording more complex (“help you plan to get help”) compared to Q24 and Q26.	—
28	To what extent does your doctor...suggest things you can do to cope with your concerns and fears about cancer?	Most respondents felt this question was redundant—same as Q24.	Drop Q28, because it is narrower than Q24, which covers cancer-related stress more generally.	—
Scales		Most respondents had no problems.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
Overall		<p>Most respondents forgot that questions follow from the stem.</p> <p>Most respondents felt that questions were repetitive.</p> <p>One respondent had more than one type of cancer and had different responses to questions depending on which type of cancer he was referencing.</p> <p>Several respondents had difficulty distinguishing between cancer and cancer care, even though they previously indicated there was a distinction.</p> <p>One respondent indicated that answers would be different for different providers.</p>	—	<ol style="list-style-type: none"> 1. Reformat stem—Need to change formatting of stem to make it more apparent that it applies to the following questions and/or need instructions for how to answer questions (pointing out stem). 2. Consider eliminating some questions. 3. Consider asking questions about more than main provider.

Appendix Q. Objective 3: Summary Findings and Recommendations: Managing Uncertainty

Managing uncertainty (7 respondents)

Question Number	Current Wording	Findings	Recommendations	Additional Notes
Instructions	<p>During medical care, there may be situations where there is not a clear answer or where doctors and patients don't know the answer to an important question. For example, experts sometimes disagree about which treatment is best, or doctors cannot be sure which side effects will occur during treatment. These types of situations can cause uncertainty for patients.</p> <p>The next section asks about the uncertainties you have experienced in your care. It also asks how you and your main doctor have discussed or dealt with these uncertainties.</p>	<p>Most patients understood the general concept of uncertainty but had difficulty applying it. In other words, most knew what the term "uncertainty" meant; however, they did not know how to interpret it for this survey.</p> <p>One patient commented: "I have a hard time with...uncertainty. There are some things that nobody knows. Then there are things that I don't know, but my doctor does. And there are things that I think I know, but I'm going to ask my doctor just to be sure."</p> <p>Some patients also experienced uncertainties that they felt were unimportant, not distressing, or easily clarified. (For instance, one patient was curious where she should go for radiation treatment; her doctor easily provided a referral.) Patients were unsure whether to count these instances as "uncertainties."</p>	—	<p>Consider distinguishing between genuine scientific uncertainty (i.e., no one knows the answer) vs. patient uncertainty (i.e., patient does not know answer to critical issue) vs. patient curiosity (i.e., patient does not know answer to minor issue). Patients saw these as different concepts and had difficulty lumping them together under the term "uncertainty."</p> <p>After segmenting these concepts, consider (a) asking about each type of uncertainty in turn or (b) tailoring the instructions to reference the desired type of uncertainty.</p>

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
1 (Overall)	What types of uncertainties have you experienced in the course of your cancer care?	Most patients had difficulty answering Q1. In some cases, patients were still confused about the definition of “uncertainty.” In other cases, patients selected questions if the topic was brought up in conversation rather than the topic being a genuine uncertainty. (For instance: One patient checked “What kind of side effects...” not because she was uncertain about the side effects but because she asked her doctor this question.)	Change to yes/no response options	Revise this section’s instructions to focus on one type of uncertainty, which may alleviate confusion about Q1. Alternatively, consider adopting a new answer scale: I experienced this uncertainty, but my doctor knew the answer. I experienced this uncertainty, and my doctor did not know the answer. I did not experience this uncertainty.
1A	What is my diagnosis?	No problems.	—	—
1B	What is my prognosis?	Some patients—especially those with less education—did not understand the term “prognosis.”	What is my prognosis (i.e., life expectancy, chances that cancer can be cured)?	Alternatively, split this question into multiple questions. What are the chances that I will survive my cancer? What are the chances that my cancer can be cured? If my cancer cannot be cured, how long do I have to live?
1C	What are the treatment choices?	No problems.	—	—
1D	Which treatment will be best for me?	No problems.	—	—
1E	What are the chances of my cancer coming back?	One patient felt this question overlapped with Q1B. Otherwise, no problems.	—	—
1F	What kinds of side effects I will have from treatment?	No problems.	—	—
1G	How I will cope with side effects of treatment?	No problems.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
1H	Where should I go for treatment?	One patient was unsure how to interpret this question. She wondered if the question was addressing uncertainty about treatment providers (i.e., What organization will provide my treatment?) or uncertainty about a facility's location (i.e., Where is the hospital located?).	What hospital or clinic will provide my treatment?	—
1I	How do I choose a doctor?	No problems.	—	—
1J	What do different doctors and health care providers do?	Some patients were confused by this question and were unsure what it was asking.	Which doctors do I go to for different services?	—
1K	Will health insurance cover my treatment?	No problems.	—	—
1L	Will I be able to work during (or after) treatment?	No problems.	—	—
1M	Can I carry out my family responsibilities during (or after) treatment?	No problems.	—	—
1N	Can I continue with my usual activities during (or after) treatment?	No problems.	—	—
1O	How will cancer affect my everyday life?	No problems.	—	—
1P	How should I tell my family or friends about my cancer?	One patient commented that family and friends should be separated. Otherwise, no problems.	—	—
1Q	What are my rights as a patient?	A few patients were unsure how to interpret the phrase "rights as a patient."	What are my rights as a patient (e.g., choosing my doctor, making decisions about my treatment)?	Provide parenthetical examples.
1R	What is my role in making decisions about my care?	No problems.	—	—
1S	What is my family's role in making decisions about my care?	No problems.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
1T	Other issues or situations	<p>Patients cited several other uncertainties that they experienced:</p> <ul style="list-style-type: none"> • Who will support and help with my care? • How long will it take to recover after treatment? • Who should I tell about my cancer? • How do I make sense of health insurance bills? • Should I get a second opinion? 	—	Consider adding these questions to Q1.
2	Has your doctor ever told you that sometimes there are uncertainties in cancer care?	No problems.	—	Patients had no apparent difficulty answering this question. However, many were unsure how to define “uncertainty,” which may skew responses. See earlier comments.
3	How often do you and your doctor...discuss uncertainties?	A few patients indicated that they discussed uncertainties at the time of diagnosis or treatment decisions. They were less likely to discuss uncertainties after treatment ended.	—	Consider a different stem for Q3 or provide a time frame.
4	How often do you and your doctor...discuss your questions about the uncertainties?	A few patients indicated that they discussed uncertainties at the time of diagnosis or treatment decisions. They were less likely to discuss uncertainties after treatment ended.	—	Consider a different stem for Q4 or provide a time frame.
5	How well does your doctor...identify possible sources of uncertainty in your cancer care?	Patients were confused by the phrase “sources of uncertainty” and were unsure what the question was asking.	Drop question. Replace with Q6 instead.	—
6	How well does your doctor...explain the reasons for uncertainty in your cancer care?	A few patients were confused by the phrase “reasons for uncertainty;” however, most had no difficulty answering the question.	How well does your doctor...explain why these uncertainties exist? -or- Did your doctor explain why these uncertainties exist? [If yes] How well did he explain this?	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
7	How well does your doctor...share the information you want about the uncertainties that affect your cancer care?	One patient thought the “how well...” stem was inappropriate because the question was not relevant to her care. She desired the “how often...” stem instead. Otherwise, no problems.	—	—
8	How well does your doctor...help you make sense of the uncertainties?	One patient thought the “how well...” stem was inappropriate because the question was not relevant to her care. She desired the “how often...” stem instead. Otherwise, no problems.	—	—
9	How well does your doctor...explain uncertainties caused by experts not having enough information?	Patients interpreted “experts” as doctors with substantial experience or “doctors who see a lot of patients.” Some patients could not process the scenario presented in this question (i.e., uncertainties caused by a lack of evidence). They first had to recall an uncertainty that was caused by lack of information, and they then had to recall how well their doctor explained it. Cognitively, this seemed like too much for some patients.	Drop question. Replace with revised Q6 instead.	This question may be too complex or nuanced for patients to comprehend. Consider dropping it and asking, in general, how well the doctor explained why uncertainties exist in the patient’s cancer care.
10	How well does your doctor...explain the uncertainties that experts disagree about?	Patients interpreted “experts” as doctors with substantial experience or “doctors who see a lot of patients.” Some patients could not process the scenario presented in this question (i.e., uncertainties caused by scientific disagreement). They first had to recall an uncertainty that was caused by disagreement, and they then had to recall how well their doctor explained it. Cognitively, this seemed like too much for some patients.	Drop question. Replace with revised Q6 instead.	This question may be too complex or nuanced for patients to comprehend. Consider dropping it and asking, in general, how well the doctor explained why uncertainties exist in the patient’s cancer care.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
11	How well does your doctor...help you understand why experts have different opinions about your type of cancer care?	Patients interpreted “experts” as doctors with substantial experience or “doctors who see a lot of patients.” Some patients could not process the scenario presented in this question (i.e., uncertainties caused by scientific disagreement). They first had to recall an uncertainty that was caused by different opinions, and they then had to recall how well their doctor explained it. Cognitively, this seemed like too much for some patients. Other patients stated this scenario was not relevant to their care. They did not recall experts having different opinions about their cancer care.	Drop question. Replace with revised Q6 instead.	This question may be too complex or nuanced for patients to comprehend. Consider dropping it and asking, in general, how well the doctor explained why uncertainties exist in the patient’s cancer care.
12	How well does your doctor...respond to your feelings and emotions about the uncertainties of your cancer care?	No problems.	—	—
13	How well does your doctor...help you manage the uncertainties of your cancer care?	Several patients thought Q13 and Q14 were redundant. However, other patients thought the questions were distinct. They thought “manage” meant to functionally or practically deal with uncertainty and thought “cope” meant to emotionally deal with uncertainty.	—	Retain question. Monitor it for overlap with Q14 during large-scale testing.
14	How well does your doctor...help you cope with the uncertainties of your cancer care?	Several patients thought Q13 and Q14 were redundant. However, other patients thought the questions were distinct. They thought “manage” meant to functionally or practically deal with uncertainty and thought “cope” meant to emotionally deal with uncertainty.	—	Retain question. Monitor it for overlap with Q13 during large-scale testing.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
15	To what extent does your doctor...let you know about the uncertainties before you ask about them?	Most patients had no difficulty with this question. However, a few thought it was unrealistic for a doctor to address uncertainties before the patient raised them.	—	—
16	To what extent does your doctor...try to understand what you are uncertain about in your cancer care?	No problems.	—	—
17	To what extent does your doctor...comfort and reassure you about the uncertainties of your cancer care?	No problems. Patients interpreted “comfort” to mean “tell me it’s okay” or “watch me carefully.”	—	—
18	To what extent does your doctor...comfort and reassure your family or caregivers about the uncertainties of your cancer care?	No problems.	—	—
19	To what extent does your doctor...explain the uncertainties of your cancer care in a way that is easy to understand?	No problems.	—	—
20	To what extent does your doctor...help you handle the uncertainties of your cancer care?	No problems.	—	—
21	To what extent does your doctor...help you feel a sense of control in your cancer care?	Most patients had no difficulty with this question. They interpreted “sense of control” as “taking care of myself” and “handling my care.” However, one patient offered a fatalistic response: “I don’t feel a sense of control. But do we have control? Not really.”	—	Retain question. Monitor it for fatalistic responses in large-scale testing.

Appendix R. Objective 3: Summary Findings and Recommendations: Making Decisions

Making decisions (8 respondents)

Question Number	Current Wording	Findings	Recommendations	Additional Notes
Instructions				
1	To what extent do you and your doctor discuss...how much <u>you</u> want to be involved in making decisions about your cancer care?	No problems. Patients did not perceive much difference between “would like” and “want.” Patients considered “cancer care” as being a broader term than “cancer treatment.”	—	—
2	To what extent do you and your doctor discuss...how much you want <u>your family or caregivers</u> to be involved in making decisions about your cancer care?	No problems. Two respondents had different interpretations of “caregiver.” One patient defined “caregiver” as “someone other than family member—government agency,” and another defined it as “anyone involved in the patient’s care—from doctor to hospital employees.”	—	Confusion over the meaning of the term “caregiver” needs to be investigated further. Confusion on the part of two people does not warrant changing the wording of the question.
3	To what extent do you and your doctor discuss...what matters most to <u>you</u> when making decisions about your cancer care?	No problems. Patients did not perceive a difference between “what is most important to you” and “what matters most.” Two patients preferred “what is most important to you” and one preferred currently wording (others did not state a preference).	What is most important to <u>you</u> when making decisions about your cancer care?	—
4	To what extent do you and your doctor discuss...what matters most to <u>your family or caregivers</u> when making decisions about your cancer care?	No problems. (Same as above)	What is most important to <u>your family or caregivers</u> when making decisions about your cancer care?	—
5	To what extent do you and your doctor discuss...what kinds of support would be helpful to you in making decisions (e.g., talking with other patients, talking with other healthcare providers)?	No problems. Other examples of support that patients listed included Web sites, printed information, support groups, and expert panels.	—	One patient suggested adding other examples to this question, such as support groups or the American Cancer Society.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
6	To what extent do you and your doctor discuss...how different treatment choices would affect <u>you</u> ?	Two patients said they did not have any options for treatment, so unsure how to answer. One respondent was unsure whether question referred to effectiveness or side effects associated with different options.	Address in instructions/call attention to Does Not Apply response option.	—
7	To what extent do you and your doctor discuss...how different treatment choices would affect <u>your family or caregivers</u> ?	Three patients said this was less important than Q6 because focus should be on how treatment affects patient.	Drop question because attention to effects on family is lower priority.	—
8	To what extent do you and your doctor discuss...his or her recommendations for your cancer care?	No problems.	—	—
9	To what extent does your doctor...make it clear when there are decisions to be made about your cancer care?	Two patients prefer “decisions to make” rather than “to be made.”	Make it clear when there are decisions to make about your cancer care?	—
10	To what extent does your doctor...explain the different choices in your cancer care?	Three patients said they did not have different treatment choices, so did not know how to answer. Need to rephrase or introduce, so that they consider all kinds of decisions, not just a choice between treatment A and treatment B.	Address in instructions/call attention to Does Not Apply response option.	—
11	To what extent does your doctor...explain the advantages and disadvantages of different treatment choices, before making decisions about your care?	Two patients perceived Q11 and Q12 as asking the same thing and preferred Q12. One participant interpreted advantages/disadvantages in terms of survival rates.	Drop question.	Determine whether important to ask about both advantages/disadvantages and risks/benefits.
12	To what extent does your doctor...explain the risks and benefits of different choices, before making decisions about your care?	No problems. Risks were interpreted in terms of side effects.	—	—
13	To what extent does your doctor...check how well you understand the different choices in your care?	No problems. One respondent said question not relevant since she did not have choices.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
14	To what extent does your doctor...show interest in what you have to say about the different choices?	No problems.	—	—
15	To what extent does your doctor...suggest ways you can be involved in making decisions about your care?	No problems.	—	—
16	To what extent does your doctor...suggest things to think about that help you make decisions about your cancer care?	Several prefer “things to consider” versus “things to think about.”	Suggest things to consider that help you make decisions about your cancer care?	—
17	To what extent does your doctor...share the information you need to help you make decisions?	No problems.	—	—
18	To what extent does your doctor...share materials (e.g., brochures or other written materials, DVDs or videos, Web sites) to help you in making decisions?	Two patients suggested moving the examples to the end of the question—they are distracting where they appear. One suggested adding books.	Share materials to help you in making decisions (e.g., brochures or other written materials, DVDs or videos, Web sites, books)?	—
19	How well does your doctor...explain the different choices in your cancer care?	Three patients indicated that this question was irrelevant to their situations because they interpreted in terms of treatment options and they did not have options.	Address in instructions/call attention to Does Not Apply response option.	One patient suggested adding “Before making decisions about your care” before “how well does your doctor...” in the question stem.
20	How well does your doctor...answer your questions about different treatment options?	Two patients said that this question was redundant with Q19 (likely because they interpreted both questions in terms of treatment decisions).	—	Determine whether important to ask about both advantages/disadvantages and risks/benefits.
21	How well does your doctor...explain the advantages and disadvantages of different treatment choices, before making decisions about your care?	Most patients thought this question was redundant with other questions. They generally preferred Q22 (risks and benefits) over Q21 (advantages and disadvantages). Thought “before making decisions about your cancer” unnecessary.	Drop question.	Consider whether important to ask both the “to what extent” (Q11 and Q12) and “how well” questions. Determine whether important to ask about both advantages/disadvantages and risks/benefits

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
22	How well does your doctor...explain the risks and benefits of different choices, before making decisions about your care	No problems. Thought "before making decisions about your care" unnecessary.	Explain the risks and benefits of different choices?	One patient suggested adding the phrase "you make your" between the words "before" and "making decisions..." in the question.
23	How well does your doctor...explain his or her recommendations for your cancer care?	No problems.	—	—
24	After making decisions about your cancer care, to what extent does your doctor...review decisions to make sure you understand them?	No problems.	—	—
25	After making decisions about your cancer care, to what extent does your doctor...confirm your agreement with the decision before moving on to other issues?	No problems.	—	—
26	After making decisions about your cancer care, to what extent does your doctor...check that you understand what the decision will mean for you?	One respondent was unsure about how to interpret question (referring to negative effects?); one respondent said redundant with Q24.	Drop question.	Further testing would be beneficial to determine if "what the decisions will mean" should be revised. See Q30 and Q31.
27	After making decisions about your cancer care, to what extent does your doctor...check that you understand what the decision will mean for your family (or caregivers)?	One respondent said redundant with Q24.	Drop question.	One participant unclear about "caregivers." See Q30 and Q31.
28	After making decisions about your cancer care, to what extent does your doctor...ask if you are satisfied with how the decision was made?	Most respondents said providers did not discuss this; one said not relevant; unclear if they thought this type of discussion was desirable and important.	—	Further testing would be beneficial.
29	After making decisions about your cancer care...to what extent do you and your doctor discuss....any questions you have about taking the next steps in your care?	No problems.	—	One patient commented that this question was most relevant for active treatment.
30	After making decisions about your cancer care...what the decision will mean for you?	Several respondents were unsure about how to interpret "will mean for you" (e.g., consequences, side effects, existential).	Drop question.	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
31	After making decisions about your cancer care...what the decision will mean for your family (or other caregivers)?	Same as Q30.	Drop question.	—
32	After making decisions about your cancer care...any problems you might have carrying out the decision?	Most patients thought this question was unclear and/or not relevant because they did not need to do much to carry out the decision (did not require them to do anything on their own, just “show up” for treatment); several patients unclear how to interpret.	Drop question.	—
33	To what extent do you and your doctor discuss...how the decision worked out for <u>you</u> ?	No problems.	—	“How the decision worked out” was interpreted by one patient as getting tests done after treatment to detect progress; another interpreted it in terms of side effects.
34	To what extent do you and your doctor discuss...how the decision worked out for <u>your family or caregivers</u> ?	No problems.	—	—
35	To what extent do you and your doctor discuss...how the decision affected your quality of life?	No problems.	—	“Quality of life” was described by patients as “refers to limitation, the impact on the ability to go out, and interact with others”; “interpreted as pertaining to illness, progress, and side effects”; and “how you operate on a daily basis, how it affects the things that you do.”
36	To what extent do you and your doctor discuss...any problems you had in carrying out the decision?	One patient unsure if refers to doctor’s or patient’s decision; several patients said not relevant as decision did not require that they do anything on their own (same as Q32).	Drop question.	—
37	To what extent do you and your doctor discuss...whether to make any changes to the decision?	Several patients said not relevant because they did not have options.	Drop question.	—

Appendix S. Objective 3: Summary Findings and Recommendations: Enabling Self-Management

Enabling self-management (7 participants)

Question Number	Current Wording	Findings	Recommendations	Additional Notes
Instructions	These questions focus on how you and your doctor talk about managing your cancer, your treatment, and your health, especially between visits to the doctor.	Participants understood the instructions regarding cancer management, indicating that this would involve diagnosis, treatment, and monitoring of the condition.	—	—
1	To what extent do you and your doctor discuss...how cancer is affecting your everyday life?	Participants understood the general distinction between “cancer” and “cancer care.” One person had slight difficulty but understood the general idea. They described everyday activities as work, transportation, cooking, and social outings. Change to <u>your</u> cancer to be consistent with Q3 and 4.	To what extent do you and your doctor discuss...how <u>your</u> cancer is affecting your everyday life?	—
2	To what extent do you and your doctor discuss...how your cancer care is affecting your everyday life?	All patients understood the general distinction between “cancer” and “cancer care.” One person had slight difficulty but understood the idea.	—	Continue using the phrase “cancer care” in the measurement items.
3	To what extent do you and your doctor discuss...how cancer is affecting your family’s everyday life?	One participant asked if the question was referring to her cancer. Another participant did not include his wife (because she is part of the health care visit) when considering his family, believing the question referred to other family members.	To what extent do you and your doctor discuss...how <u>your</u> cancer is affecting your family’s everyday life?	Define “family” somewhere in the survey.
4	To what extent do you and your doctor discuss...how your cancer care is affecting your family’s everyday life?	No problems. But change question to be consistent with previous question.	To what extent do you and your doctor discuss...how <u>your</u> cancer care is affecting your family’s everyday life?	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
5	To what extent do you and your doctor discuss...what is important to <u>you</u> when planning your cancer care?	One participant said this question "is a good one." Two participants said they look to their doctor to tell them what is important.	—	There is some overlap between Q5 and Q7. Reword to separate them as much as possible.
6	To what extent do you and your doctor discuss...what is important to your <u>family or caregivers</u> when planning your cancer care?	A less educated participant said he would answer the question differently for "family" vs. "caregivers." Ask about one or the other in this single question. Another participant interpreted the question as asking her about the family's preferences. Interpreted question as asking what she thinks is important for her family.	Drop question.	Do not ask about both "family" and "caregivers" in any single question.
7	To what extent do you and your doctor discuss...your ideas and preferences when planning your cancer care?	One participant said he does not have any ideas—he does what the doctor tells him. Another participant suggested focusing on preferences instead of ideas. Drop ideas.	To what extent do you and your doctor discuss...your preferences when planning your cancer care?	Could also ask about whether doctor discussed the patient's questions or concerns if this not covered elsewhere.
8	To what extent does your doctor...let you know when it's time to change your cancer care plan?	Several participants said this question was not relevant to them. One person said "let you know" sounded condescending.	Drop question.	—
9	To what extent does your doctor...discuss what will happen next in your cancer care?	No problems. One person did not feel this was relevant because he was still in treatment, but it is relevant at many points in cancer care and across the cancer continuum.	—	—
10	To what extent does your doctor...make sure <u>you</u> understand what will happen next in your cancer care?	Some felt there was overlap between Q9 and Q10, but they address different concepts.	—	—
11	To what extent does your doctor...make sure your family or caregivers understand what will happen next in your cancer care?	One participant interpreted "caregiver" as the nurse.	To what extent does your doctor...make sure your family understands what will happen next in your cancer care?	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
12	To what extent does your doctor...check if you are having problems following your cancer care plan?	Three participants thought of “side effects” when they read “problems.” Another suggested using the word “challenges.” One participant did not know what was meant by “cancer care plan.”	To what extent does your doctor...check how you are doing following the plans for your cancer care?	Define cancer care plan if that term is used. Question requires additional testing since “checking on how you are doing” may be the responsibility of someone else on the doctor’s staff.
13	To what extent does your doctor...discuss how to deal with problems that make it hard to follow your cancer care plan?	One participant was not sure if treatment was the “cancer care plan.” One participant did not feel this question was relevant since he is still in treatment.	Drop—reworded version of Q12 addresses this.	—
14	To what extent does your doctor....discuss how your family or caregiver can make it easier for you to follow your cancer care plan?	Unclear who the discussion is with— the doctor and patient, or the doctor and the family member.	Drop—too complicated.	—
15	How well does your doctor....explain what steps are needed to get the cancer care you need?	Question was clear. One participant indicated that because of the type of cancer and the nature of the treatment, he did not need to know any additional information. He indicated that he was sure his doctor would provide help or information if needed, but that he did not need anything at this point. This applied to Q16 through Q19 as well.	How well does your doctor....explain the steps for getting the cancer care you need?	—
16	How well does your doctor...coordinate with other health care providers to make sure you get the cancer care you need?	No problems.	—	Highly redundant with questions in cross-cutting (Q13 and Q14) and fostering healing relationships (Q33 and Q34) functions. Consider all of these questions together and drop some.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
17	How well does your doctor...help you coordinate with other health care providers to make sure you get the cancer care you need?	No problems. People seemed to recognize the difference between Q16 and Q17.	—	Highly redundant with questions in cross-cutting (Q13 and Q14) and fostering healing relationships (Q33 and Q34) functions. Consider all of these questions together and drop some.
18	To what extent does your doctor...ask you about the cancer care you receive from other healthcare providers?	No problems. One person said this was not relevant to her because she only had surgery.	—	—
19	To what extent does your doctor...discuss problems you might have in getting the cancer care you need?	No problems. But the word “problems” was unclear in an earlier question.	To what extent does your doctor...ask about any problems you might have had getting the care you need?	Consider rewording this for a yes/no response.
20	To what extent does your doctor....discuss how your culture might affect how your cancer care is delivered.	Multiple respondents said culture was not relevant to their cancer care.	Further testing required.	—
21	To what extent does your doctor help you find resources for...managing your own health (e.g., help with diet, exercise, stress)?	Not clear whether question is referring to aside from one's cancer care or including it and whether question is referring to cancer doctor or another doctor. Both of these issues were addressed in the prior instructions.	—	Question may need instructions reminding respondent to think of their main cancer doctor because these questions get at health promotion topics typically addressed by PCPs.
22	To what extent does your doctor help you find resources for...getting the cancer care you need (e.g., help with transportation, cost of medications)?	One participant said these examples do not apply because he is insured.	Drop question. Too heavily focused on insurance-related issues.	Alternatively, change the example, but other issues are addressed with later questions.
23	To what extent do you and your doctor discuss...the goals for your health?	A few participants did not know whether these goals were related to their cancer or health goals in general. Instructions are provided to address this but seemed to have been missed by some.	To what extent do you and your doctor discuss....your goals for your health?	Clarify the goals are the patient's goals.

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
24	To what extent do you and your doctor discuss...changes you can make to take better care of your health (such as diet, exercise, dealing with stress)?	No problems.	Drop question. See Q30 below.	Consider dropping examples in parentheses because they were overemphasized.
25	To what extent do you and your doctor discuss...ways you can manage side effects or symptoms?	No problems. One participant said he had no side effects because he did not have chemotherapy.	—	—
26	To what extent do you and your doctor discuss...ways you can take care of yourself at home?	Some people noted overlap between Q24 and Q26.	—	Could choose Q24 or Q26. Could more directly compare the two in further testing.
27	To what extent do you and your doctor discuss...ways that your family or caregivers can take care of you at home?	No problems.	To what extent do you and your doctor discuss...ways that your family can take care of you at home?	—
28	To what extent do you and your doctor discuss...questions or concerns you have about managing your health?	No problems. One participant said he does not know what questions to ask.	—	—
29	To what extent do you and your doctor discuss...the kinds of support you need to manage your own health?	No problems.	—	—
30	How often do you and your doctor discuss...ways to manage your own health (such as diet, exercise, dealing with stress)?	One participant said he prefers Q30 instead of Q24, but Q24 assumes the person's health needs to be improved.	—	Consider dropping if too much emphasis on this topic across all questions.
31	How often do you and your doctor discuss...ideas for managing your own health?	Two participants felt Q31 was addressed in Q30.	Drop question.	—
32	How often do you and your doctor discuss...how you are doing with your goals for managing your health?	One participant said she did not think it was important how often this was discussed, but that it was discussed at least once.	—	Consider changing to yes/no. Move adjacent to questions addressing goals.

Appendix T. Objective 3: Summary Findings and Recommendations: Cross-Cutting Items

Cross-cutting items (7 respondents)

Question Number	Current Wording	Findings	Recommendations	Additional Notes
Instructions	(Communicating with Your Doctor): These questions ask about how your doctor communicates with you.	No problems.	—	—
1	To what extent does your doctor...listen carefully to what you have to say?	No problems.	—	—
2	To what extent does your doctor...treat you with courtesy and respect?	No problems.	—	—
3	To what extent does your doctor...treat your family or caregivers with courtesy and respect?	No problems.	—	—
4	To what extent does your doctor...limit interruptions during your appointments?	No problems.	—	—
5	To what extent does your doctor...give you his or her full attention?	No problems.	—	—
6	To what extent does your doctor...make sure there is privacy during your appointments?	No problems.	—	—
7	To what extent does your doctor...make sure he or she can focus on you during your appointments?	No problems.	—	—
8	To what extent does your doctor...spend enough time with you?	No problems.	—	—
9	To what extent does your doctor...make the best use of the time with you?	No problems.	—	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
10	To what extent does your doctor...take the time to address your questions and concerns?	One patient felt this question was double-barreled and that “questions” and “concerns” should be asked about separately. Patient did not know how to answer; doctor addressed questions but not concerns.	1. To what extent does your doctor...take the time to address your questions? 2. To what extent does your doctor...take the time to address your concerns?	Consider splitting into two separate questions.
Instructions	(Roles and Responsibilities)	—	—	—
11	To what extent does your doctor...explain the roles and responsibilities of other healthcare providers involved in your care?	No problems.	—	—
12	To what extent does your doctor...explain who is in charge of your care?	No problems.	—	—
13	To what extent does your doctor...seem to communicate with other healthcare providers so that they are up-to-date with test results and the cancer care you receive?	No problems. One patient indicated that they liked the phrase “seem to.”	Drop question (narrower than Q14).	One patient preferred this question to Q4, because it was clearer. Considering dropping either Q13 or Q14.
14	To what extent does your doctor...seem to work with other healthcare providers involved in your cancer care?	Two patients felt this question was too similar to Q13 and did not see the distinction between “work with” and “communicate.” Of those, one patient reported that Q13 was clearer. One patient wondered if this question was about communication <i>skills</i> (rather than communication). One patient was unclear what other health care providers were being referenced.	—	One patient preferred Q13 but expressed that if using both questions (Q13 and Q14) the distinction between “work with” and “communicate” be made clearer. Consider providing examples of other health care providers (e.g., primary care physician, nurses, nutritionist). Consider dropping either Q13 or Q14.

Note: We recommend moving Q33 and Q34 from fostering healing relationships and Q16 and Q17 from enabling self-management to cross-cutting; these questions are closely related to Q13 and Q14 above.

(Fostering Healing Relationships) How well does your doctor seem to communicate...

33. with other healthcare providers who help take care of you?

34. with other health care providers to make sure that you get the care you need?

(Enabling self-management) How well does your doctor....

16. coordinate with other healthcare providers to make sure you get the cancer care you need?

17. help you coordinate with other healthcare providers to get the cancer care you need?

Appendix U. Objective 3: Background

Background (7 respondents)

Question Number	Current Wording	Findings	Recommendations	Additional Notes
Instructions	The next few questions ask about your cancer diagnosis and treatment.	No problems.	—	—
1	When was the first time that a doctor or other healthcare professional told you that you had cancer? <input type="checkbox"/> Less than 3 months ago <input type="checkbox"/> More than 3 months ago but less than 12 months ago <input type="checkbox"/> 1 to 2 years ago <input type="checkbox"/> More than 2 years ago but less than 5 years ago <input type="checkbox"/> 5 or more years ago	No problems.	—	Two patients referred to a prior cancer diagnosis (not current cancer); determine if question should ask about first diagnosis or current diagnosis; could add a question asking if they have been diagnosed with cancer more than once and, if so, when their more recent diagnosis was.
2	What type(s) of cancer have you ever been diagnosed with? (check all that apply) <input type="checkbox"/> Bladder cancer <input type="checkbox"/> Breast cancer <input type="checkbox"/> Colorectal cancer (cancer of the colon or rectum) <input type="checkbox"/> Endometrial cancer <input type="checkbox"/> Hodgkin's lymphoma (or Hodgkin's Disease) <input type="checkbox"/> Kidney cancer (renal cell) <input type="checkbox"/> Leukemia <input type="checkbox"/> Lung cancer <input type="checkbox"/> Melanoma <input type="checkbox"/> Non-Hodgkin lymphoma <input type="checkbox"/> Pancreatic cancer <input type="checkbox"/> Prostate cancer <input type="checkbox"/> Skin cancer (other than melanoma) <input type="checkbox"/> Other type of cancer (specify) <input type="checkbox"/> Don't know	No problems. Few types of cancer not listed that came up in responses: ovarian cancer, cervical cancer, head and neck.	Consider adding other types of cancer (based on prevalence).	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
3	<p>What is your cancer treatment status?</p> <p><input type="checkbox"/> I have not yet started my cancer treatment → Skip to Q6</p> <p><input type="checkbox"/> I am currently receiving treatment</p> <p><input type="checkbox"/> I have completed my active cancer treatment (can still be taking medication to prevent recurrence, or the cancer coming back),</p> <p><input type="checkbox"/> I will not receive cancer treatment (e.g., watchful waiting) → Skip to Q6</p> <p><input type="checkbox"/> Don't know</p>	<p>Two respondents were confused because surgery was not listed; they did not consider surgery as "treatment."</p> <p>Two participants found the parenthetical information in third response option confusing (One respondent had finished active treatment but was not taking medication; was unsure whether to select this response).</p>	<p>Add an introduction to Q3 and Q4 that clarifies surgery is considered treatment.</p> <p>Revise the parenthetical information in third response option:</p> <p><input type="checkbox"/> I have completed my active cancer treatment (you can check this option even if you are still taking medication to prevent recurrence, or the cancer is coming back).</p>	—
4	<p>What type(s) of cancer treatment have you ever received? (Check all that apply)</p> <p><input type="checkbox"/> I have not received any medical treatment for cancer → Skip to Q6</p> <p><input type="checkbox"/> Surgery (do not consider biopsy or insertion of medication ports to be surgery)</p> <p><input type="checkbox"/> Chemotherapy (include both IV, that is intravenous, and oral forms of chemotherapy)</p> <p><input type="checkbox"/> Radiation therapy</p> <p><input type="checkbox"/> Hormonal therapy</p> <p><input type="checkbox"/> Bone marrow or stem cell transplant (do not consider bone marrow biopsy to be a transplant)</p> <p><input type="checkbox"/> Targeted, biologic and immune therapies</p> <p><input type="checkbox"/> Complementary or alternative medicine</p> <p><input type="checkbox"/> Other medical treatments (please specify)</p> <p><input type="checkbox"/> Don't know</p>	<p>Some respondents were unfamiliar with some types of treatment: targeted, biologic, and immune therapies.</p> <p>Complementary or alternative medicine—respondents not using this form of treatment did not understand this category, also asked if herbals are included.</p> <p>Some participants found the exclusion for surgery and chemo (in parentheses) confusing and/or insulting. For surgery, did 'not understand why biopsy excluded. Were 'not sure whether to include lymph node removal as surgery. Referring to biopsy, "It hurt and I have the scar to prove it"; "they still cut you."</p>	<p>Add an introduction to Q3 and Q4 that clarifies surgery is considered treatment.</p> <p>Revise wording about surgery so that it does not say biopsy and insertion of medication ports are not surgery, for example,</p> <p><input type="checkbox"/> Surgery (note: do include biopsy or insertion of medication ports)</p>	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
5	When was the <u>last time</u> you received any of these treatments for your cancer? <input type="checkbox"/> Less than 3 months ago <input type="checkbox"/> More than 3 months ago but less than 12 months ago <input type="checkbox"/> 1 to 2 years ago <input type="checkbox"/> More than 2 years ago but less than 5 years ago <input type="checkbox"/> 5 or more years ago	No problems.	—	—
6	At any time since you were first diagnosed with cancer, did a doctor or other health care professional tell you that your cancer had come back (i.e., had a recurrence)? <ul style="list-style-type: none"> • Yes • No → Skip to Q8 	No problems.	—	—
7	[If yes] When was your most recent recurrence? <ul style="list-style-type: none"> • Less than 3 months ago • More than 3 months ago but less than 12 months ago • 1 to 2 years ago • More than 2 years ago but less than 5 years ago • 5 or more years ago 	No problems.	—	—
	The next questions ask about the <u>main</u> doctor who is treating (or treated) your cancer. Your main doctor is the doctor you consider to be in charge of your cancer care. If you have had more than one main doctor since you were first diagnosed with cancer, please answer these questions about your most recent main doctor.	Most of the respondents skipped the instructions because of Q6's skip instructions.	Revise skip instructions to direct respondents to this introduction.	—

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Question Number	Current Wording	Findings	Recommendations	Additional Notes
8	<p>What is your main doctor's area of specialty?</p> <p><input type="checkbox"/> Primary care (such as internal medicine, family practice)</p> <p><input type="checkbox"/> Medical oncologist or hematologist</p> <p><input type="checkbox"/> Radiation oncologist</p> <p><input type="checkbox"/> Surgeon</p> <p><input type="checkbox"/> Gastroenterologist</p> <p><input type="checkbox"/> Dermatologist</p> <p><input type="checkbox"/> Urologist</p> <p><input type="checkbox"/> Other (please specify)</p> <p><input type="checkbox"/> Don't know</p>	<p>One respondent did not understand difference between medical and radiation oncologist: wanted to add: surgical oncologist, gynecologist.</p>	<p>Revise response options to add surgical oncologist and gynecologist/gyn onc:</p> <p><input type="checkbox"/> Primary care (such as internal medicine, family practice)</p> <p><input type="checkbox"/> Medical oncologist or hematologist</p> <p><input type="checkbox"/> Radiation oncologist</p> <p><input type="checkbox"/> Surgeon/surgical oncologist</p> <p><input type="checkbox"/> Gynecologist/ gynecological oncologist</p> <p><input type="checkbox"/> Gastroenterologist</p> <p><input type="checkbox"/> Dermatologist</p> <p><input type="checkbox"/> Urologist</p> <p><input type="checkbox"/> Other (please specify)</p> <p><input type="checkbox"/> Don't know</p>	—
9	<p>Is your main doctor male or female?</p> <p><input type="checkbox"/> Male</p> <p><input type="checkbox"/> Female</p>	No problems.	—	—
10	<p>How long have you been going to this doctor for any kind of medical care?</p> <p><input type="checkbox"/> Less than 3 months</p> <p><input type="checkbox"/> More than 3 months but less than 12 months</p> <p><input type="checkbox"/> 1 to 2 years</p> <p><input type="checkbox"/> More than 2 years but less than 5 years</p> <p><input type="checkbox"/> 5 or more years</p>	No problems.	—	—
11	<p>In the last 12 months, how many times did you see your main doctor?</p> <p><input type="checkbox"/> One time</p> <p><input type="checkbox"/> Two times</p> <p><input type="checkbox"/> Three times</p> <p><input type="checkbox"/> Four times</p> <p><input type="checkbox"/> Five to nine times</p> <p><input type="checkbox"/> Ten or more times</p>	<p>Respondents who had been hospitalized for cancer treatment (chemotherapy surgery, radiation, etc.) were unsure whether/how to count their contact with the doctor while in the hospital.</p> <p>Two participants calculated how many times they had seen their doctor per month; one had difficulty translating this into the response options. Include higher number of visits (these two participants had seen their doctor two times a month so that would be 24 visits).</p>	<p>In the last 12 months, about how many times did you see your main doctor?</p> <p><input type="checkbox"/> Not at all</p> <p><input type="checkbox"/> 1–2 times</p> <p><input type="checkbox"/> 3–5 times</p> <p><input type="checkbox"/> 5–9 times</p> <p><input type="checkbox"/> 10–20 times</p> <p><input type="checkbox"/> More than 20 times</p>	<p>Consider adding: If you saw your doctor during a hospital stay, count each time he or she visited you while you were in the hospital.</p>

Appendix V. Objective 4: Draft PCC Patient Survey Items

This set of draft PCC patient survey items reflects the findings from the cognitive testing. Draft survey items are presented for the following functions as defined in the NCI conceptual model of PCC: fostering healing relationships, exchanging information, making decisions, enabling patient self-management, and responding to emotions, as well as crosscutting functions (Epstein, R.M., & Street, R.L., Jr. (2007). *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. Bethesda, MD: National Cancer Institute). Note that there are no items for the managing uncertainty function, as the cognitive testing identified significant issues with the draft managing uncertainty items. Consequently, we recommend further formative research and that additional item development and testing be conducted for this function.

Sample Physician PCC Items

	All of the time	Most of the time	Some of the time	None of the time		Don't Know	Does Not Apply
1. How often do you and your patients discuss...							
a. ...what they already know and understand about their cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...their concerns and questions about their cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...their concerns and questions about their cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

	≥75% of the time	50–74% of the time	25–49% of the time	<25% of the time		Don't Know	Does Not Apply
2. How often do you and your patients discuss...							
a. ...how cancer is affecting their everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...how cancer is affecting their family's everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...what is important to them in planning their cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

	All of my patients	Most of my patients	Some of my patients	None of my patients		Don't Know	Does Not Apply
3. With how many of your patients do you discuss the following...							
a. ...their feelings related to their cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...how they are coping emotionally with their cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...things they can do to cope with their concerns and fears about their cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

	Very much	A fair amount	Somewhat	A little	Not at all		Don't Know	Does Not Apply
4. To what extent do you and your patients regularly discuss...								
a. ...their goals for their health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...ways they can manage side effects and symptoms?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...ways they can take care of themselves at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Exchanging Information

Instructions: The next few questions ask about the information that you and your main doctor might discuss.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
1. To what extent do you and your doctor discuss...							
a. ...what you already know and understand about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...what you already know and understand about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...your concerns and questions about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...your concerns and questions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...how much information you would like to have about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...how much information you would like to have about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
2. To what extent does your doctor...							
a. ...show interest in your cancer experience?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...ask you to share your cancer experience with him or her?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...make you feel comfortable asking questions or talking about your concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...make it easy for you to share personal or sensitive information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...listen carefully to what you have to say about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...listen carefully to what you have to say about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
3. How often does your doctor...								
a. ...give you helpful information, even when you don't ask for it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...suggest information that is helpful to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...make sure you have the information you need and want?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...show you pictures, graphs, or other materials to help you understand important information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...give you or tell you about brochures, written information, or other materials that are helpful to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...tell you where you can get other information you need (e.g. from websites, organizations)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g. ...explain things in a way that is clear and easy to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
h. ...help you understand the information you need to know about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
i. ...help you understand the information you need to know about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
j. ...check to be sure your questions are answered?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
k. ...let you know if you misunderstood any information about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
l. ...let you know if you misunderstood any information about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
4. To what extent does your doctor...									
a.	...check to see what kinds of information you would like to have about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b.	...check to see what kinds of information you would like to have about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c.	...discuss information that you get from other places (e.g., information you find on the Internet)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Sometimes, doctors have to share difficult (or “bad”) news with cancer patients.

5. Has your doctor ever had to share any bad news with you about your cancer?

☐ Yes → Go to 6

☐ No → Stop

☐ Don't know → Stop

☐ Does Not Apply → Stop

6. Has your doctor asked how you would like to learn about any bad news?

☐ Yes

☐ No

☐ Does Not Apply

7. Does your doctor share bad news with you in the way that you like?

☐ Yes

☐ No

☐ Does Not Apply

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8. How well does your doctor share bad news in a way that is sensitive to your needs and feelings?

- ☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor

- ☐ Don't know
☐ Does Not Apply

Fostering Healing Relationships

Instructions: The next few questions ask about things that your doctor may have done to build a good relationship with you and your family.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All	Don't Know	Does Not Apply
1. To what extent does your doctor...							
a. ...try to get to know you as an individual person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...treat you as a person, not just another patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...show real concern for you and your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...remember details about you between visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...show that he or she cares about you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...show that he or she cares about your health needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...consider what is best for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. ...show commitment to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. ...show commitment to taking care of you as long as needed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. ...show interest in your personal background?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. ...show interest in your culture?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
2. To what extent do you and your doctor...							
a. ...discuss how you will work together as a team during your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...discuss his or her role in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...discuss how you would like to be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...discuss his or her desire for you to be actively involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...discuss how you would like your family to be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
3. To what extent does your doctor...							
a. ...encourage you to share information openly and honestly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...have open and honest communication with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...make you feel comfortable sharing information openly and honestly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...share complete and honest information with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...share complete and honest information with your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
4. To what extent does your doctor talk in a way that makes you...								
a. ...feel he or she is well informed about your type of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...feel he or she is up-to-date with the latest treatment choices for your type of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...trust in his or her ability to provide you with the care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...trust him or her with personal or sensitive information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

5. As far as you are aware, have there been any medical mistakes^f or errors occurred in your cancer care?

- ☐ Yes → Go to 5A
- ☐ No → Skip to next section

- ☐ Don't Know → Skip to next section
- ☐ Does Not Apply → Skip to next section

5A. Did your doctor discuss the medical mistake or error with you?

- ☐ Yes → Continue
- ☐ No → Stop

- ☐ Does Not Apply → Stop

5B. How well did your doctor discuss the medical mistake or error with you?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

- ☐ Does Not Apply

^f Medical mistakes and errors might include receiving the wrong medication or dosing, the wrong or unnecessary treatment, misinterpretation of laboratory results, misdiagnosis, or surgical errors.

Recognizing and Responding to Emotions

Instructions: People diagnosed with cancer sometimes have different feelings throughout their cancer care. This set of questions asks about your communication with your doctor about your feelings.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
1. How often do you and your doctor discuss...								
a. ...how you are coping emotionally with your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...how you are coping emotionally with your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...your feelings related to your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...your feelings related to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...how you are coping with your feelings related to your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...things you can do to cope with your concerns and fears about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
2. To what extent does your doctor...									
a.	...make you feel comfortable to talk about your fears, worries, or other feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b.	...seem to know if you are feeling sad or blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c.	...show that he or she is aware of your feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d.	...let you know that patients with cancer often have feelings similar to yours?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e.	...show concern for your feelings, not just your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f.	...show sensitivity to your feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g.	...show concern about how you are doing emotionally?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
h.	...show concern for how your family is doing emotionally?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
i.	...show an understanding of your concerns and fears about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
j.	...comfort and reassure you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
k.	...give you emotional support?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
l.	...reassure you about your concerns about cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
m.	...reassure you about his or her commitment to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
n.	...help you think about ways to deal with the stress of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
o.	...help you think about ways to deal with the stress of cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
p.	...tell you about support groups or treatments that could help you deal with your emotions related to cancer and cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Making Decisions

Instructions: There are often many different decisions to be made in cancer care, such as decisions about treatment choices, where to go for care, or how to deal with side effects. These questions ask how you and your doctor discuss and make decisions about your care. As you answer these questions, please think about all the different decisions that have been made during your cancer care.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
1. To what extent do you and your doctor discuss...								
a. ...how much you want to be involved in making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...how much you want your family to be involved in making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...what is most important to you when making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...what is most important to your family when making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...ways you can be involved in making decisions about your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...how different treatment choices would affect you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g. ...his or her recommendations for your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Does Not Apply	Don't Know
2. To what extent does your doctor...									
a.	...make it clear when there are decisions to make about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b.	...explain the different choices in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c.	...explain the risks and benefits of different choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d.	...check how well you understand the different choices in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e.	...show interest in what you have to say about the different choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f.	...share the information you need to help you make decisions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g.	...suggest things to consider that help you make decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
h.	...ask what kinds of support would be helpful to you in making decisions (e.g., talking with other patients, talking with other healthcare providers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
i.	...share materials to help you in making decisions (e.g., brochures or other written materials, DVDs or videos, web sites, books)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Excellent	Very Good	Good	Fair	Poor		Does Not Apply	Don't Know
3. How well does your doctor...									
a.	...explain the different choices in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b.	...answer your questions about different treatment choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c.	...explain the risks and benefits of different choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d.	...explain his or her recommendations for your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

These next questions ask about your discussion with your doctor after you have made a decision.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
4. After making decisions about your cancer care, to what extent does your doctor...								
a. ...review decisions to make sure you understand them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...confirm your agreement with the decision before moving on to other issues?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...answer any questions you have about taking the next steps in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...ask if you are satisfied with how the decision was made?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

These next questions ask about your discussion with your doctor after you have had carried out a decision.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
5. To what extent do you and your doctor discuss...								
a. ...how the decision worked out for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...how the decision worked out for your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...how the decision affected your quality of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Managing Your Cancer, Your Treatment, and Your Health

Instructions: These questions focus on how you and your doctor talk about managing your cancer, your treatment, and your health, especially between visits to the doctor.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
1. To what extent do you and your doctor discuss...							
a. ...how your cancer is affecting your everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...how your cancer care is affecting your everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...how your cancer is affecting your family's everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...how your cancer care is affecting your family's everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
2. To what extent do you and your doctor discuss...							
a. ...what is important to you when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...your preferences when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
3. To what extent does your doctor...									
a.	...discuss what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b.	...make sure you understand what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c.	...make sure your family understands what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d.	...check how well you are following the plans for your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
4. To what extent does your doctor...									
a.	...explain the steps for getting the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b.	...ask you about the cancer care you receive from other healthcare providers?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c.	...ask about any problems you might have had getting the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d.	...help you find resources for managing your own health (e.g., help with diet, exercise, stress)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e.	...discuss how your culture might affect your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

In some cases, doctors discuss ways that you can manage your own health during and after your cancer care.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
5. To what extent do you and your doctor discuss...								
a. ...your goals for your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...ways you can manage your side effects or symptoms?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...ways you can take care of yourself at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...ways that your family can take care of you at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...questions or concerns you have about managing your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...the kinds of support you need to manage your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

	Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
6. How often do you and your doctor discuss...								
a. ...ways to manage your own health (such as diet, exercise, dealing with stress)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...how you are doing with your goals for managing your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Crosscutting

Instructions: The next few questions ask about how your doctor communicates with you.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
1. To what extent does your doctor...							
a. ...listen carefully to what you have to say?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...treat you with courtesy and respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...treat your family with courtesy and respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...limit interruptions during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...give you his or her full attention?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...make sure there is privacy during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...make sure he or she can focus on you during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. ...spend enough time with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. ...make the best use of the time with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. ...take the time to address your questions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. ...take the time to address your concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
2. To what extent does your doctor...							
a. ...explain the roles and responsibilities of other health care providers involved in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...explain who is in charge of your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Excellent	Very Good	Good	Fair	Poor		Don't Know	Does Not Apply
3. How well does your doctor...									
a.	...coordinate with other health care providers to make sure you get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b.	...help you coordinate with other health care providers to get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c.	...seem to work with other health care providers involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Background / Demographics

Instructions: The next few questions ask about your cancer diagnosis and treatment.

1. Have you been diagnosed with cancer more than once?

- ☐ Yes → [Go to Q2A]
☐ No → [Go to Q2B]

2A. [If multiple cancer diagnoses] Please think about your most recent type of cancer. How long ago were you diagnosed with your most recent cancer?

- ☐ Less than 3 months ago
☐ More than 3 months ago but less than 12 months ago
☐ 1 to 2 years ago
☐ More than 2 years ago but less than 5 years ago
☐ 5 or more years ago

2B. [If single cancer diagnosis] When was the first time that a doctor or other healthcare professional told you that you had cancer?

- ☐ Less than 3 months ago
☐ More than 3 months ago but less than 12 months ago
☐ 1 to 2 years ago
☐ More than 2 years ago but less than 5 years ago
☐ 5 or more years ago

3. What type(s) of cancer have you ever been diagnosed with? (check all that apply)

- ☐ Bladder cancer
- ☐ Breast cancer
- ☐ Cervical cancer
- ☐ Colorectal cancer (cancer of the colon or rectum)
- ☐ Endometrial cancer
- ☐ Head or neck cancer
- ☐ Hodgkin's lymphoma (or Hodgkin's Disease)
- ☐ Kidney cancer (renal cell)
- ☐ Leukemia
- ☐ Lung cancer
- ☐ Melanoma
- ☐ Non-Hodgkin lymphoma
- ☐ Ovarian cancer
- ☐ Pancreatic cancer
- ☐ Prostate cancer
- ☐ Skin cancer (other than melanoma)
- ☐ Other type of cancer (specify)

☐ Don't know

The next few questions ask about your cancer treatment. There are many types of cancer treatment, including surgery, chemotherapy, radiation therapy, and many other options.

Sometimes doctors do a biopsy to find out if you have cancer. This usually is not a type of treatment.

4. What is your cancer treatment status?

- ☐ I have not yet started my cancer treatment → Skip to Q7
- ☐ I am currently receiving treatment
- ☐ I have completed my active cancer treatment
- ☐ I have completed my active cancer treatment, but I'm still taking medication to prevent the cancer from coming back
- ☐ I will not receive cancer treatment (e.g., watchful waiting) → Skip to Q7

☐ Don't know

5. What type(s) of cancer treatment have you ever received? (Check all that apply)

- ☐ I have not received any medical treatment for cancer → Skip to Q6
- ☐ Surgery
- ☐ Chemotherapy (both intravenous (IV) and oral forms of chemotherapy)
- ☐ Radiation therapy
- ☐ Hormonal therapy
- ☐ Bone marrow or stem cell transplant (do not consider bone marrow biopsy to be a transplant)
- ☐ Targeted, biologic and immune therapies
- ☐ Complementary or alternative medicine
- ☐ Other medical treatments (please specify)

☐ Don't know

6. When was the last time you received any of these treatments for your cancer?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

7. At any time since you were first diagnosed with cancer, did a doctor or other health care professional tell you that your cancer had come back (i.e., had a recurrence)?

- ☐ Yes
- ☐ No → Skip to Instructions before Q9

8. [If yes] When was your most recent recurrence?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

The next questions ask about the main doctor who is treating (or treated) your cancer. Your main doctor is the doctor you consider to be in charge of your cancer care. If you have had more than one main doctor since you were first diagnosed with cancer, please answer these questions about your most recent main doctor.

9. What is your main doctor's area of specialty?

- ☐ Primary care (such as internal medicine, family practice),
 - ☐ Medical oncologist or hematologist
 - ☐ Radiation oncologist
 - ☐ Surgeon / surgical oncologist
 - ☐ Gynecologist / gynecological oncologist
 - ☐ Gastroenterologist
 - ☐ Dermatologist
 - ☐ Urologist
 - ☐ Other (please specify)
-
- ☐ Don't know

10. Is your main doctor male or female?

- ☐ Male
- ☐ Female

11. How long have you been going to this doctor for any kind of medical care?

- ☐ Less than 3 months
- ☐ More than 3 months but less than 12 months
- ☐ 1 to 2 years
- ☐ More than 2 years but less than 5 years
- ☐ 5 or more years

12. In the last 12 months, how many times did you see your main doctor? If you were in the hospital, please count each time he or she saw you as a separate visit.

- ☐ Not at all
- ☐ 1-2 times
- ☐ 3-5 times
- ☐ 6-9 times
- ☐ 10-20 times
- ☐ More than 20 times

Exchanging Information

Instructions: The next few questions ask about the information that you and your main doctor might discuss.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
9. To what extent do you and your doctor discuss...								
a. ...what you already know and understand about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...what you already know and understand about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...your concerns and questions about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...your concerns and questions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...how much information you would like to have about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...how much information you would like to have about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
10. To what extent does your doctor...								
a. ...show interest in your cancer experience?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...ask you to share your cancer experience with him or her?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...make you feel comfortable asking questions or talking about your concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...make it easy for you to share personal or sensitive information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...listen carefully to what you have to say about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...listen carefully to what you have to say about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

	Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
11. How often does your doctor...								
a. ...give you helpful information, even when you don't ask for it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...suggest information that is helpful to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...make sure you have the information you need and want?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...show you pictures, graphs, or other materials to help you understand important information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...give you or tell you about brochures, written information, or other materials that are helpful to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...tell you where you can get other information you need (e.g. from websites, organizations)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g. ...explain things in a way that is clear and easy to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
h. ...help you understand the information you need to know about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
i. ...help you understand the information you need to know about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
j. ...check to be sure your questions are answered?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
k. ...let you know if you misunderstood any information about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
l. ...let you know if you misunderstood any information about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All	Does Not Apply	
							Don't Know	
12. To what extent does your doctor...								
a.	...check to see what kinds of information you would like to have about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
b.	...check to see what kinds of information you would like to have about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
c.	...discuss information that you get from other places (e.g., information you find on the Internet)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>

Sometimes, doctors have to share difficult (or “bad”) news with cancer patients.

13. Has your doctor ever had to share any bad news with you about your cancer?

☐ Yes → Go to 6

☐ No → Stop

☐ Don't know → Stop

☐ Does Not Apply → Stop

14. Has your doctor asked how you would like to learn about any bad news?

☐ Yes

☐ No

☐ Does Not Apply

15. Does your doctor share bad news with you in the way that you like?

☐ Yes

☐ No

☐ Does Not Apply

16. How well does your doctor share bad news in a way that is sensitive to your needs and feelings?

- ☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor

☐ Don't know
☐ Does Not Apply

Fostering Healing Relationships

Instructions: The next few questions ask about things that your doctor may have done to build a good relationship with you and your family.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
5. To what extent does your doctor...								
a. ...try to get to know you as an individual person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...treat you as a person, not just another patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...show real concern for you and your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...remember details about you between visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...show that he or she cares about you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...show that he or she cares about your health needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g. ...consider what is best for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
h. ...show commitment to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
i. ...show commitment to taking care of you as long as needed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
j. ...show interest in your personal background?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
k. ...show interest in your culture?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

							Does Not Apply		Don't Know	
		Very Much	A Fair Amount	Somewhat	A Little	Not at All				
6. To what extent do you and your doctor...										
a.	...discuss how you will work together as a team during your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
b.	...discuss his or her role in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
c.	...discuss how you would like to be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
d.	...discuss his or her desire for you to be actively involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
e.	...discuss how you would like your family to be involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>

							Does Not Apply		Don't Know	
		Very Much	A Fair Amount	Somewhat	A Little	Not at All				
7. To what extent does your doctor...										
a.	...encourage you to share information openly and honestly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
b.	...have open and honest communication with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
c.	...make you feel comfortable sharing information openly and honestly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
d.	...share complete and honest information with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>
e.	...share complete and honest information with your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>			<input type="radio"/>	<input type="radio"/>

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
8. To what extent does your doctor talk in a way that makes you...								
a. ...feel he or she is well informed about your type of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...feel he or she is up-to-date with the latest treatment choices for your type of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...trust in his or her ability to provide you with the care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...trust him or her with personal or sensitive information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

5. As far as you are aware, have there been any medical mistakes^g or errors occurred in your cancer care?

- ☐ Yes → Go to 5A
- ☐ No → Skip to next section
- ☐ Don't Know → Skip to next section
- ☐ Does Not Apply → Skip to next section

5A. Did your doctor discuss the medical mistake or error with you?

- ☐ Yes → Continue
- ☐ No → Stop

- ☐ Does Not Apply → Stop

5B. How well did your doctor discuss the medical mistake or error with you?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

- ☐ Does Not Apply

^g Medical mistakes and errors might include receiving the wrong medication or dosing, the wrong or unnecessary treatment, misinterpretation of laboratory results, misdiagnosis, or surgical errors.

Recognizing and Responding to Emotions

Instructions: People diagnosed with cancer sometimes have different feelings throughout their cancer care. This set of questions asks about your communication with your doctor about your feelings.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Always	Often	Sometimes	Rarely	Never		Don't Know	Does Not Apply
3. How often do you and your doctor discuss...								
a. ...how you are coping emotionally with your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...how you are coping emotionally with your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...your feelings related to your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...your feelings related to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...how you are coping with your feelings related to your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...things you can do to cope with your concerns and fears about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
4. To what extent does your doctor...									
a.	...make you feel comfortable to talk about your fears, worries, or other feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b.	...seem to know if you are feeling sad or blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c.	...show that he or she is aware of your feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d.	...let you know that patients with cancer often have feelings similar to yours?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e.	...show concern for your feelings, not just your illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f.	...show sensitivity to your feelings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g.	...show concern about how you are doing emotionally?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
h.	...show concern for how your family is doing emotionally?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
i.	...show an understanding of your concerns and fears about your cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
j.	...comfort and reassure you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
k.	...give you emotional support?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
l.	...reassure you about your concerns about cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
m.	...reassure you about his or her commitment to your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
n.	...help you think about ways to deal with the stress of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
o.	...help you think about ways to deal with the stress of cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
p.	...tell you about support groups or treatments that could help you deal with your emotions related to cancer and cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

Making Decisions

Instructions: There are often many different decisions to be made in cancer care, such as decisions about treatment choices, where to go for care, or how to deal with side effects. These questions ask how you and your doctor discuss and make decisions about your care. As you answer these questions, please think about all the different decisions that have been made during your cancer care.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
6. To what extent do you and your doctor discuss...								
a. ...how much you want to be involved in making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...how much you want your family to be involved in making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...what is most important to you when making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...what is most important to your family when making decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...ways you can be involved in making decisions about your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...how different treatment choices would affect you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g. ...his or her recommendations for your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
7. To what extent does your doctor...							
a. ...make it clear when there are decisions to make about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...explain the different choices in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...explain the risks and benefits of different choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...check how well you understand the different choices in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...show interest in what you have to say about the different choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...share the information you need to help you make decisions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...suggest things to consider that help you make decisions about your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. ...ask what kinds of support would be helpful to you in making decisions (e.g., talking with other patients, talking with other healthcare providers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. ...share materials to help you in making decisions (e.g., brochures or other written materials, DVDs or videos, web sites, books)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Poor	Fair	Good	Very Good	Excellent
8. How well does your doctor...							
a. ...explain the different choices in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...answer your questions about different treatment choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...explain the risks and benefits of different choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...explain his or her recommendations for your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These next questions ask about your discussion with your doctor after you have made a decision.

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
9. After making decisions about your cancer care, to what extent does your doctor...							
a. ...review decisions to make sure you understand them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...confirm your agreement with the decision before moving on to other issues?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...answer any questions you have about taking the next steps in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...ask if you are satisfied with how the decision was made?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These next questions ask about your discussion with your doctor after you have had carried out a decision.

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
10. To what extent do you and your doctor discuss...							
a. ...how the decision worked out for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...how the decision worked out for your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...how the decision affected your quality of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Managing Your Cancer, Your Treatment, and Your Health

Instructions: These questions focus on how you and your doctor talk about managing your cancer, your treatment, and your health, especially between visits to the doctor.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
7. To what extent do you and your doctor discuss...							
a. ...how your cancer is affecting your everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...how your cancer care is affecting your everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...how your cancer is affecting your family's everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...how your cancer care is affecting your family's everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
8. To what extent do you and your doctor discuss...							
a. ...what is important to you when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...your preferences when planning your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
9. To what extent does your doctor...							
a. ...discuss what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...make sure you understand what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...make sure your family understands what will happen next in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...check how well you are following the plans for your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
10. To what extent does your doctor...							
a. ...explain the steps for getting the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...ask you about the cancer care you receive from other healthcare providers?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...ask about any problems you might have had getting the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...help you find resources for managing your own health (e.g., help with diet, exercise, stress)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...discuss how your culture might affect your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In some cases, doctors discuss ways that you can manage your own health during and after your cancer care.

	Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
11. To what extent do you and your doctor discuss...							
a. ...your goals for your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...ways you can manage your side effects or symptoms?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...ways you can take care of yourself at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...ways that your family can take care of you at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...questions or concerns you have about managing your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...the kinds of support you need to manage your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Does Not Apply	Don't Know	Never	Rarely	Sometimes	Often	Always
12. How often do you and your doctor discuss...							
a. ...ways to manage your own health (such as diet, exercise, dealing with stress)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...how you are doing with your goals for managing your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Crosscutting

Instructions: The next few questions ask about how your doctor communicates with you.

Please note:

- Most questions are presented in groups.
- For each group of questions, the first part of the question is the same.
- Please read the first part of the question as you answer each question in the group.

	Very Much	A Fair Amount	Somewhat	A Little	Not at All		Don't Know	Does Not Apply
4. To what extent does your doctor...								
a. ...listen carefully to what you have to say?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
b. ...treat you with courtesy and respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
c. ...treat your family with courtesy and respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
d. ...limit interruptions during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
e. ...give you his or her full attention?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
f. ...make sure there is privacy during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
g. ...make sure he or she can focus on you during your appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
h. ...spend enough time with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
i. ...make the best use of the time with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
j. ...take the time to address your questions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
k. ...take the time to address your concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>

		Does Not Apply	Don't Know	Not at All	A Little	Somewhat	A Fair Amount	Very Much
5. To what extent does your doctor...								
a.	...explain the roles and responsibilities of other health care providers involved in your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b.	...explain who is in charge of your care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Does Not Apply	Don't Know	Poor	Fair	Good	Very Good	Excellent
6. How well does your doctor...								
a.	...coordinate with other health care providers to make sure you get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b.	...help you coordinate with other health care providers to get the cancer care you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c.	...seem to work with other health care providers involved in your cancer care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Background / Demographics

Instructions: The next few questions ask about your cancer diagnosis and treatment.

2. Have you been diagnosed with cancer more than once?

- ☐ Yes → [Go to Q2A]
☐ No → [Go to Q2B]

2A. [If multiple cancer diagnoses] Please think about your most recent type of cancer. How long ago were you diagnosed with your most recent cancer?

- ☐ Less than 3 months ago
☐ More than 3 months ago but less than 12 months ago
☐ 1 to 2 years ago
☐ More than 2 years ago but less than 5 years ago
☐ 5 or more years ago

2B. [If single cancer diagnosis] When was the first time that a doctor or other healthcare professional told you that you had cancer?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

13. What type(s) of cancer have you ever been diagnosed with? (check all that apply)

- ☐ Bladder cancer
 - ☐ Breast cancer
 - ☐ Cervical cancer
 - ☐ Colorectal cancer (cancer of the colon or rectum)
 - ☐ Endometrial cancer
 - ☐ Head or neck cancer
 - ☐ Hodgkin's lymphoma (or Hodgkin's Disease)
 - ☐ Kidney cancer (renal cell)
 - ☐ Leukemia
 - ☐ Lung cancer
 - ☐ Melanoma
 - ☐ Non-Hodgkin lymphoma
 - ☐ Ovarian cancer
 - ☐ Pancreatic cancer
 - ☐ Prostate cancer
 - ☐ Skin cancer (other than melanoma)
 - ☐ Other type of cancer (specify)
-
- ☐ Don't know

The next few questions ask about your cancer treatment. There are many types of cancer treatment, including surgery, chemotherapy, radiation therapy, and many other options.

Sometimes doctors do a biopsy to find out if you have cancer. This usually is not a type of treatment.

14. What is your cancer treatment status?

- ☐ I have not yet started my cancer treatment → Skip to Q7
- ☐ I am currently receiving treatment
- ☐ I have completed my active cancer treatment
- ☐ I have completed my active cancer treatment, but I'm still taking medication to prevent the cancer from coming back
- ☐ I will not receive cancer treatment (e.g., watchful waiting) → Skip to Q7

- ☐ Don't know

15. What type(s) of cancer treatment have you ever received? (Check all that apply)

- ☐ I have not received any medical treatment for cancer → Skip to Q6
- ☐ Surgery
- ☐ Chemotherapy (both intravenous (IV) and oral forms of chemotherapy)
- ☐ Radiation therapy
- ☐ Hormonal therapy
- ☐ Bone marrow or stem cell transplant (do not consider bone marrow biopsy to be a transplant)
- ☐ Targeted, biologic and immune therapies
- ☐ Complementary or alternative medicine
- ☐ Other medical treatments (please specify)

- ☐ Don't know

16. When was the last time you received any of these treatments for your cancer?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

17. At any time since you were first diagnosed with cancer, did a doctor or other health care professional tell you that your cancer had come back (i.e., had a recurrence)?

- ☐ Yes
- ☐ No → Skip to Instructions before Q9

18. [If yes] When was your most recent recurrence?

- ☐ Less than 3 months ago
- ☐ More than 3 months ago but less than 12 months ago
- ☐ 1 to 2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago

The next questions ask about the main doctor who is treating (or treated) your cancer. Your main doctor is the doctor you consider to be in charge of your cancer care. If you have had more than one main doctor since you were first diagnosed with cancer, please answer these questions about your most recent main doctor.

19. What is your main doctor's area of specialty?

- ☐ Primary care (such as internal medicine, family practice),
- ☐ Medical oncologist or hematologist
- ☐ Radiation oncologist
- ☐ Surgeon / surgical oncologist
- ☐ Gynecologist / gynecological oncologist
- ☐ Gastroenterologist
- ☐ Dermatologist
- ☐ Urologist
- ☐ Other (please specify)

☐ Don't know

20. Is your main doctor male or female?

- ☐ Male
- ☐ Female

21. How long have you been going to this doctor for any kind of medical care?

- ☐ Less than 3 months
- ☐ More than 3 months but less than 12 months
- ☐ 1 to 2 years
- ☐ More than 2 years but less than 5 years
- ☐ 5 or more years

22. In the last 12 months, how many times did you see your main doctor? If you were in the hospital, please count each time he or she saw you as a separate visit.

- ☐ Not at all
- ☐ 1-2 times
- ☐ 3-5 times
- ☐ 6-9 times
- ☐ 10-20 times
- ☐ More than 20 times